UNDERSTANDING THE LIVED EXPERIENCE OF PEOPLE WITH OSTOMIES AND THEIR HEALTH CARE EXPERIENCES TO INFORM DIETETIC PRACTICE

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Abstract

Individuals undergo an adjustment process after ostomy surgery which includes changes in physical abilities, relationships, body image, diet, and social activities. While researchers encourage health care providers (HCPs) to assist people as they learn to cope with changes, there are few guidelines and no standardized training to help dietitians address the psychosocial concerns of people with ostomies. The purpose of this thesis was to better understand how to offer relevant and effective dietetic counselling for people with ostomies. We designed three studies to explore the lifestyle, nutrition, and food-related concerns of people living with ostomies, the current practices of dietitians who counsel people with ostomies, and dietitians' interactions within an interdisciplinary health care team.

I extracted data from Reddit's r/ostomy (an online community of people with ostomies) using keyword searches related to food and nutrition, and I conducted 10 semi-structured interviews with people living with ostomies in Newfoundland and Labrador (NL). I also conducted 21 semi-structured interviews with dietitians, nurses, physicians, and ostomy support group leaders who care for and support people with intestinal ostomies in NL. We qualitatively analyzed all data and coded themes using two initial coders and Nvivo software.

We found that people with ostomies were concerned about physical, psychosocial, and behavioural changes such as ostomy leakage, and changes in mental health, diet, and the ability to sleep. In addition, people with ostomies learned to manage their appliances and output over time by forming new routines, and many commented on the positive role that peer support played throughout their adaptation. Overall, most HCPs focused on physical health and providing in-hospital care to people with ostomies.

Our findings suggest there is a lack of psychosocial support and resources available to people with an ostomy, and variable practices of interdisciplinary care and long-term follow-up. Future research should include a longitudinal study to observe how people with new ostomies receive dietetic counselling and cope with changes over time. Additionally, quality assurance studies should be conducted to better understand potential gaps in health services. Lastly, standardized training should be designed and offered to dietitians to support person-centred dietetic counselling for people with ostomies.

General Summary

After having ostomy surgery, people experience changes in physical abilities, relationships, body image, diet, and social activities. Researchers encourage health care providers (HCPs) to assist people as they learn to cope with changes, but there are few guidelines and no standardized training to help dietitians address the mental, emotional, and social concerns of patients with ostomies. The purpose of this thesis was to better understand how to offer relevant and effective dietetic counselling for people with ostomies. We designed three studies to help us better understand the lifestyle, nutrition, and food-related concerns of people living with ostomies, how dietitians provide care to people with ostomies, and how dietitians work and communicate with other HCPs.

I downloaded social media posts from Reddit's r/ostomy (an online forum for people with ostomies) by searching for keywords related to food and nutrition, and I conducted 10 interviews with people living with ostomies in Newfoundland and Labrador (NL). I also conducted 21 interviews with dietitians, nurses, physicians, and ostomy support group leaders, who care for and support people with ostomies in NL. We analyzed all data by highlighting recurring ideas (themes) using Nvivo software.

We found that people with ostomies were concerned about physical, psychosocial, and behavioural changes such as ostomy leakage, and changes in mental health, diet, and the ability to sleep. People with ostomies learned to manage their appliances and output over time by forming new routines; many commented on the positive role that peer support provided. Overall, most HCPs focused on physical health and providing in-hospital care to people with ostomies. Our findings suggest there is a lack of mental health support and resources available to people with an ostomy, and that the practice of team-based care and long-term follow-up are inconsistent. Future studies should aim to observe how people with new ostomies receive dietetic counselling and cope with changes over time. Additionally, studies should be conducted to better understand potential gaps in health services so that the quality of care can be improved. Lastly, standardized training should be designed and offered to dietitians to support person-centred dietetic counselling for people with ostomies.

Positionality Statement

There are many patient and health care provider (HCP) interactions that have stood out to me since my time as a dietetic intern, and they have stayed with me. I've ruminated and reflected on each one, often asking myself, "Why do you remember this moment in particular? You have seen hundreds of patients - why this one? Why that sentence? Why that face?" For some of those memories, I'm still working on the answers to those questions. As a dietitian, health services researcher, and a previous patient, I am continuously seeking a better understanding of people's health care experiences.

During my dietetic internship, my preceptor and I received a referral for a man who required parenteral nutrition (nutrition through intravenous support). This man had an ostomy due to bowel disease and he was instructed not to eat during his stay in the hospital. His doctors had ordered parenteral nutrition because they determined he needed complete bowel rest. I vividly remember this man saying that he "was not much of a man" as he pointed to his ostomy appliance. At that moment, I felt unprepared, I felt uncomfortable. I saw a man who was unaccepting of his health status because he was determined to maintain his employment and care for his family. From my observations, he was in denial of having to care for his health and he found it easier to be angry than to show sadness.

I saw many patients before and after this man who underwent surgery for a new ostomy. One of the conditions of patients' discharge was dietetic counselling so that they could manage their diet with an ostomy. As I witnessed several patients have difficulty coping with a change in their health status, I began to wonder how HCPs help people adjust to changed health status, and what patients expect of HCPs during a time of illness.

I asked myself, “what can we as HCPs do to better understand the patient experience? Why did having an ostomy make a patient feel ‘less like a man’, and what did that really mean?” I believed that, in general, dietetic education and training did not always account for the individual context of people’s lives, the unique challenges that people face when coping will illness, or the process of adapting to illness. I knew these considerations were complex, and I sought an increased understanding of people’s experiences living with complex medical conditions, namely those living with intestinal ostomies due to bowel disease.

Co-Authorship Statement

Lisa Blundell is the primary author of the work enclosed in this thesis, which has been reviewed and edited by supervisors and committee members Dr. Maria Mathews, Dr. Julia Lukewich, Dr. Catherine Morley, and Dr. James Valcour. This work has been presented at conferences but has not been published prior to submitting this thesis. Publication will be sought in relevant dietetic journals such as the Journal of Critical Dietetics and the Canadian Journal of Dietetic Practice and Research, and methodology journals such as the International Journal of Qualitative Methods.

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Finally, I would like to thank my study participants. I have thoroughly enjoyed learning from your experiences and am so appreciative that you offered your time and expertise to me. To those living with illness, thank you for everything you teach others about this life and for grounding us in what truly matters.

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List of Terminology

Colostomy: a type of ostomy where a part of the colon is diverted to an opening in the abdomen.

Crohn's Disease: a type of inflammatory bowel disease, sometimes called Crohn's.

Flange: a part of the ostomy appliance that connects the ostomy bag to the stoma site.

Ileostomy: a type of ostomy where the ileum of the small intestine is diverted to an opening in the abdomen.

Ileal pouch-anal anastomosis (j-pouch): a surgery that involves creating a pouch using the small intestine which is connected to the anus to allow for elimination.

Ostomy: an opening from the small intestine or large intestine to the abdominal wall. In conversation with participants, sometimes the word ostomy is used to refer to the ostomy bag/appliance where waste is collected. It is also sometimes used interchangeably with the word 'stoma'.

Nurse Specialized in Wound, Ostomy and Continence (NSWOC): a registered nurse who has graduated from a certified program. Often referred to by older terms, enterostomal (ET) nurse or enterostomal therapist.

Stoma: a surgically created opening on the abdomen surface, constructed of intestinal tissue.

Total Parenteral Nutrition (TPN): intravenous transfusion of nutrients.

Ulcerative Colitis: a type of inflammatory bowel disease, sometimes called colitis.

List of Abbreviations

CRC .... Colorectal cancer

HCP .... Health care provider

IBD .... Inflammatory bowel disease

IPAA .... Ileal pouch-anal anastomosis

NL .... Newfoundland and Labrador

NLCHI .... Newfoundland and Labrador Centre for Health Information

NSWOC .... Nurse Specialized in Wound, Ostomy and Continence

PEN .... Practice-based Evidence in Nutrition

QOL .... Quality of life

TPN .... Total parenteral nutrition

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1.0 Introduction

Many people who experience conditions such as colorectal cancer (CRC) or inflammatory bowel disease (IBD) may require treatment that includes surgically creating an intestinal ostomy: an opening between the intestinal tract and skin (Mahan et al., 2012). CRC is the most common reason for needing an intestinal ostomy (Andersen et al., 2011; Mahan et al., 2012). Ostomies differ by their location along the intestinal tract; the most common type is a colostomy, which is an ostomy created along any part of the colon (large intestine) (McDonough, 2013). An ileostomy is an ostomy along any part of the ileum (distal end of the small intestine). Ostomies may be a permanent form of treatment, or they may be intended to be reversed at a later time (Mahan et al., 2012). Regardless of the type, ostomies require management, and it is well-documented that individuals living with ostomies undergo an adjustment process after surgery (Lopes & Decesaro, 2014). This adjustment includes changes in physical abilities, relationships, body image, sexuality, social activities, and relationship with food (Brown & Randle, 2005; Brown, 2017; Lope & Decesaro, 2014; McDonough, 2013; Thorpe & McArthur, 2017).

Health care providers (HCPs) play an important role in increasing the confidence and self-management ability of people with ostomies, and an increase in confidence is an important factor in adjustment to living with an ostomy (Lopes & Decesaro, 2014). In particular, dietitians can play an important role in ostomy management as people learn to consume an adequate diet and self-manage their ostomy at home (McDonough, 2013). Nutrition care for a person with an ostomy involves determining appropriate strategies to compensate for the loss of colonic absorptive capacity and ensuring the individual maintains an adequate nutritional status and is well hydrated (Mahan et al., 2012;

McDonough, 2013). Other nutrition-related concerns for people with colostomies include prevention of constipation and alleviation of gas and odour; concerns for people with ileostomies include managing fluid and electrolytes and preventing diarrhea or intestinal blockages (McDonough, 2013).

Dietetic counselling[1] has the potential to help a person who is adjusting to life with an ostomy as they adapt to their diet and self-manage their ostomy at home (McDonough, 2013). However, while researchers urge HCPs to assist people during their adjustment and learning to cope with changes (Lopes & Decesaro, 2014), dietetic literature does not describe how dietitians can address psychosocial concerns of people with ostomies which impact nutrition and overall health. While literature suggests that dietetic counselling can help people manage their ostomy (McDonough, 2013), there is a dearth of research that examines the role dietitians play in peoples' adjustment to life with an ostomy, and how dietitians work with other HCPs to support people in adapting to life with an ostomy.

1.1 Research Questions and Objectives

This thesis consists of three qualitative studies. The purpose of this thesis was to understand how to improve relevant and effective dietetic counselling for people with ostomies. Collectively, the three studies addressed the research questions: What are the perceived lifestyle, nutrition, and food-related concerns of people with ostomies after ostomy surgery (short-term) and during self-management (long-term)? How do dietitians

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[1] The terms *nutrition counselling* and *dietetic counselling* both exist within the literature. I chose to use dietetic counselling because I want to differentiate clearly the counselling provided by a dietitian from general nutrition advice given by a nurse, physician, gym trainer, etc.

currently counsel people living with ostomies? What do people with ostomies expect from dietetic counselling services? How do dietitians interact with the interdisciplinary care team to offer person-centred care? The objectives were:

1. To describe the nutrition, food, and lifestyle-related concerns of people living with ostomies immediately after ostomy surgery and during ongoing self-management. [Study 1, 2, and 3]
2. To describe the model of care in Newfoundland and Labrador (NL) for people with ostomies. [Study 2 and 3]
3. To describe the role of dietitians and their interactions within an interdisciplinary health care team to provide care to people with ostomies. [Study 1, 2, and 3]
4. To describe the current practices of dietitians who counsel people with ostomies. [Study 1, 2, and 3]
5. To describe patients' experiences of dietetic counselling. [Study 1, 2, and 3]

1.2 Expectations

We expected to find that people with ostomies have food-related concerns that include questions about tolerance of specific foods, controlling ostomy output, and self-managing in social settings (e.g., eating at restaurants). We also expected that people would discuss concerns about body image, travelling, changes in mental health, and quality of life (QOL). Given the focus on nutrition within the literature, we anticipated that dietitians counsel people about nutritional needs, hydration, constipation, diarrhea, and foods to control gas and odour, but less often discuss psychosocial concerns that impact the QOL of people with ostomies, such as body image, sexuality, and social activities. We also expected that the interdisciplinary team would have a narrow view of the role of dietitians that is focused primarily on routine dietary intake and ostomy output.

1.3 Research Paradigm

For this thesis, I adopted a pragmatic approach. Pragmatism is a contextual, practical approach that values problem-solving of complex social problems and achievable outcomes of research, meaning that knowledge is only meaningful if it can lead to actionable changes (Allemang et al., 2021; Giacomini, 2010; Long et al., 2018). Specifically, I used an experimental pragmatic approach, holding the belief that what is true can be verified, and what works is true (Chourasiya, 2022). Further, pragmatism is based on the idea that researchers should use the best methods and use multiple sources of data and knowledge to explore real-world problems, thereby supporting mixed method approaches (Allemang et al., 2021). Methodological choices are based on a focus to understand experiences, and research questions are driven by the social purpose of the research (Allemang et al., 2021; Long et al., 2018). Finally, a core value of pragmatism is that health research should be patient-centred, and therefore, this approach values of the lived experiences of people with disease (Allemang et al., 2021; Holtrop & Glasgow, 2020).

1.4 Rationale

As medical science progresses and the survival rates of people with chronic disease increase, it is imperative that we learn about peoples' experiences of living with chronic disease. Currently, the province of NL experiences the highest incidence rates of CRC (92.6/100,000) for both males and females in Canada (NL Centre of Health Information [NLCHI], 2015). As previously stated, many patients with CRC may require an ostomy. Information provided by NLCHI indicated that roughly 380 people undergo an intestinal ostomy surgery each year in NL (NLCHI, 2018). The large population of people with ostomies warrants research about the experiences and concerns of people with ostomies to inform the practice of HCPs and improve the health outcomes of people living with chronic bowel conditions.

Living with a new ostomy changes the lives of people and requires individuals to adjust to changes as they face everyday challenges including issues related to ‘leakage’ (i.e., when output comes in contact with skin and/or clothing), and ‘ballooning’ (i.e., air gathering in the bag; Claessens et al., 2015). Findings of a recent Cochrane Review, which focused on factors of the adaption process of living with an ostomy, indicate that there is a need to help people with ostomies find their ‘new normal’ as they redefine their identity, cope with new demands, and accept their life with an ostomy (Lopes & Decesaro, 2014). The authors of this review urged HCPs who care for individuals with ostomies to expand their knowledge and understanding of the experience and emotions involved with ostomy adaptation and to provide care that considers a person’s unique characteristics and experiences (Lopes & Decesaro, 2014). Nutrition-related concerns of individuals with ostomies indicate that a dietitian can be an important member of the health care team to support people as they adjust to a new normal.

Dietetic counselling for people living with ostomies has not been well-informed by patient needs beyond the description of the absorptive capacity of the digestive tract. Literature suggests there are important food considerations related to the eating experience with an ostomy within a social setting that should be taken into account (Brown & Randle, 2005; Brown, 2017; Thorpe & McArthur, 2017), yet these considerations are not discussed in dietetic literature. Additionally, dietetic literature about ostomy management has not yet demonstrated acknowledgment of the psychosocial adjustment to living with an ostomy. Further, there are no established clinical (dietetic) guidelines for people with ostomies, despite research demonstrating food- and nutrition-related concerns of people with ostomies (Aronovitch et al., 2010; Claessens et al., 2015; Hubbard et al., 2017; Mahan et al., 2012; McDonough, 2013). To our knowledge, research has not been conducted to determine the effectiveness of dietetic counselling for people living with ostomies within Canada. To address this gap, this thesis describes current dietetic practices and patient experiences with dietetic counselling, identifies how to provide quality care that addresses the needs of people with ostomies, and provides recommendations for dietetic practice and future research. Ultimately, this thesis can lead to improved nutrition management and psychosocial adjustment of patients with ostomies and positively impact their QOL.

1.5 Thesis Structure

This thesis consists of three separate studies that inform our research questions. To organize information, each study was separated into individual chapters (chapters three through five). Each of these chapters has subsections that detail study methods, results, and interpretation of our findings. After these three chapters, chapters six and seven provide a discussion of the results, and conclusion, respectively. In the interest of limiting repetition in the thesis, the literature that relates to cross-cutting themes in multiple studies is presented in chapter six, while the “interpretations of findings” sections of each individual study illustrate observations, explain how themes relate to one other, and discuss literature that relates to only the individual study.

2.0 Literature Review

2.1 Introduction

It is estimated that more than 750,000 people live with an ostomy in North America, and approximately 13,000 ostomy surgeries are performed each year in Canada (Vancouver United Ostomy Association Chapter, 2017). Adjusting to life with an ostomy can be very difficult for people, and there have been numerous research studies exploring the experiences of people after ostomy surgery including their experiences of health care utilization, and changes in their social environment, body image, sexuality, quality of life (QOL), and overall well-being (Brown, 2017; Brown & Randle, 2015; Claessens et al., 2015; Di Gesaro, 2016; Lopes & Decesaro, 2014; Thorpe & McArthur, 2017).

To conduct this literature review, we first looked for Canadian articles and discussion of dietetic practice and models of care for people with ostomies, then we began to look internationally as there is limited literature related to this subject. We also scanned references of each article to identify any additional literature to support this review. Many quantitative studies have been conducted using established instruments to measure an individual's adjustment to having an ostomy (e.g., Ostomy Adjustment Scale, Psychosocial Adjustment to Illness Scale Self-Report, Ostomy Adjustment Inventory-23) and the impact of an ostomy on an individual's QOL (e.g., Quality from the Patient's Perspective, Stoma Care QOL Index, Ostomy QOL Questionnaire; Aronovitch et al., 2010; Brown, 2017; Brown & Randle, 2005; Di Gesaro, 2016; Gautam & Poudel, 2016; Karabulut et al., 2014; Lopes & Decesaro, 2014). Researchers have also used qualitative methodology (typically key informant interviews) to delve into the psychosocial experiences of people living with ostomies to identify challenges of adjusting to life with an ostomy (Brown, 2017; Thorpe & McArthur, 2017). It is important to note that these studies vary greatly by the type of ostomy that participants have, the medical reason necessitating the ostomy, the length of time participants have lived with an ostomy, and participants with temporary versus permanent ostomies. Despite these variations, several literature reviews have demonstrated that people adjusting to life with an ostomy often face similar challenges and that adjustment is associated with changes in body image, sexuality, physical capabilities, relationships and social environment (Brown, 2017; Brown & Randle, 2005; Di Gesaro, 2016; Lopes & Decesaro, 2014). However, there are relatively few studies that explore the eating experience of having an ostomy or the effectiveness of dietetic counselling for people with ostomies.

2.2 Bowel Diseases and Ostomy as Treatment

Several bowel diseases may require the creation of an intestinal ostomy. Diseases that commonly include ostomy surgery as treatment include colorectal cancer (CRC), anal cancer, inflammatory bowel disease (IBD), and diverticular disease (Francone, 2021; Pemberton, 2021a). Ostomies vary by their location along the intestinal tract. Two common forms of ostomies include the ileostomy – ostomy is located along the ileum (distal) portion of the small intestine, and the colostomy – ostomy is located somewhere along the large intestine (Francone, 2021). Depending on a person's condition and prognosis, their ostomy may be reversed at a later point during their treatment, meaning that their bowel is reconnected and their stoma is closed (Francone, 2021).

Ostomy appliances (commonly called pouches or bags) can be a one-piece or a two-piece system (Figure 2.1). Both systems include a flange component (sometimes called a wafer), that is applied to the skin around the stoma, and a bag component that collects the output (Colorectal Cancer Canada, 2019). Output is often called stool in the case of a colostomy, and effluent in the case of an ileostomy. In a one-piece system, the bag cannot be detached from the flange, whereas the bag of a two-piece system can be detached and joined together as needed. Both types are drainable and the clip or Velcro at the bottom of the pouch can be opened to empty the bag as needed. All one-piece systems are disposable, whereas bags (but not flanges applied to the skin) can be reusable in two-piece systems.

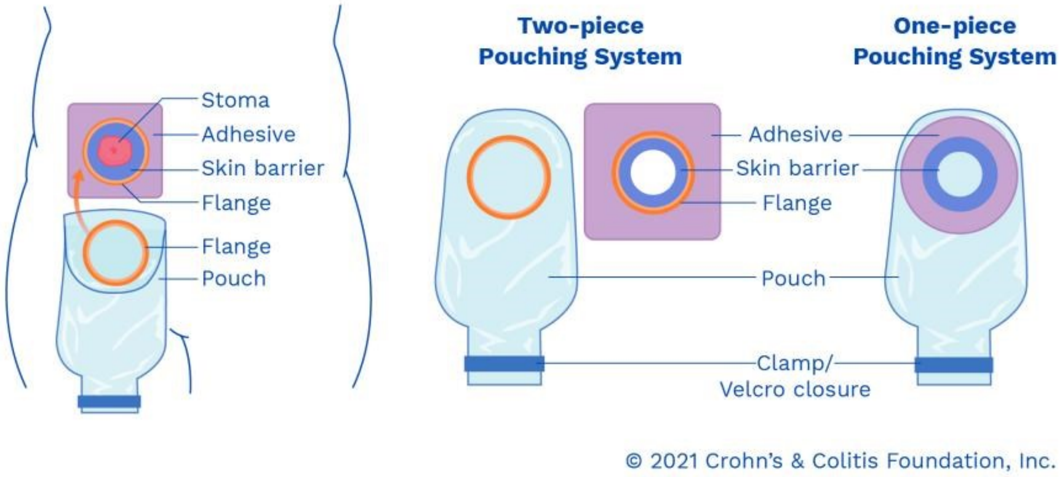

Figure 2.1

Diagram of One-Piece and Two-Piece Ostomies

Crohn's & Colitis Foundation. Copyright 2021. Reprinted from "Ostomy Tips and Tricks" at www.crohnscolitisfoundation.org. Used with permission.

Sometimes, a surgeon may choose to perform an ileal pouch-anal anastomosis (IPAA) if the patient is a suitable candidate; this procedure usually requires a temporary ileostomy as the first of two or more surgeries (Fichera, 2020). An IPAA involves removing the entire colon and rectum while preserving the anal sphincter and creating a pouch from the ileum, which functions as a reservoir for waste (Fichera, 2020). The most common form of IPAA is called a J-pouch, whereby the ileal pouch is shaped like the letter J; patients commonly use the term J-pouch rather than IPAA (Fichera, 2020). An IPAA results in continent (controlled) bowel movements; however, bowel movements tend to be frequent (as many as 12 per day in the first year after surgery, and then approximately six per day; Cleveland Clinic, 2019). A person may experience complications associated with their IPAA, such as pouchitis, an infection of the ileal pouch which occurs in 25 to 40 percent of patients (Fichera, 2020). Frequent bowel movements and the risk of pouchitis are common concerns of those considering an ileal pouch.

2.2.1 Cancer

Cancer is the most common reason that a person requires an ostomy (Andersen et al., 2011). CRC is the third most common cancer in Canada (estimated incidence of 24,800 cases in 2021; Canadian Cancer Society [CCS], n.d.-a), whereas anal cancer is relatively uncommon (incidence of 585 cases in 2016; CCS, n.d.-b). The risk of CRC increases with age; there are many additional risk factors including a family history of CRC, genetic disorders (e.g., familial adenomatous polyposis), IBD, a history of abdominopelvic radiation, weight gain between early adulthood and midlife, diabetes, tobacco use, alcohol use, race, and gender (CCS, n.d.-a; Macrae, 2022). Protective factors against CRC include physical activity and a high-fibre diet (Macrae, 2022). The primary risk factor for anal cancer is human papillomavirus infection (CCS, n.d.-b).

Treatment for colorectal and anal cancers commonly involves a combination of surgery, chemotherapy, and/or radiation therapy (Rodriguez-Bigas & Overman, 2022;

Ryan & Willett, 2021). Dietetic counselling for people with cancer is focused on countering side effects associated with treatment such as appetite suppression, vomiting, and diarrhea; the goal is to prevent malnutrition and weight loss (Dietitians of Canada, 2021). Depending on factors such as the location of the tumour(s), stage of disease, and disease symptoms, a person with CRC may have a temporary ostomy while receiving other treatment such as chemotherapy or radiation or may have a permanent ostomy and the removal of their rectum and any intestines past the site of their ostomy (Rodriguez-Begas & Overman, 2022; Ryan & Willett, 2021). For example, a person with recurring anal cancer will likely require a permanent colostomy, whereas a person with CRC who has a mass obstructing bowel movements may only require a temporary ileostomy until the cancerous mass is medically treated or removed (Rodriguez-Bigas & Overman, 2022; Ryan & Willett, 2021).

2.2.2. Inflammatory Bowel Disease

There are two forms of IBD which affect different regions and layers of the gastrointestinal tract: Crohn's disease and ulcerative colitis (Peppercorn & Cheifetz, 2021). These two immune diseases vary by their location and some clinical features, but also share some overlapping characteristics and symptoms, and both diseases often involve periods of relapse and remission during the course of treatment (Peppercorn & Cheifetz, 2021). Generally, the mechanisms that cause and exacerbate IBD are not well understood (Peppercorn & Cheifetz, 2021).

In recent years, the prevalence of IBD has been increasing globally and in 2017, there were 6.8 million cases documented around the world (Alatab et al., 2020). North America experiences the highest age-standardized prevalence rates of IBD at 422.0 cases per 100,000 people (Alatab et al., 2020). Although a person can be diagnosed with IBD at any age, it is important to note that, unlike CRC, the onset of IBD is most commonly seen in people between the ages of 15 and 30 years (Peppercorn & Cheifetz, 2021). Crohn's disease may be slightly more common in females, and in terms of ethnic and racial differences, IBD may be slightly more common amongst Jewish and White populations (Bernstein et al., 1999; Karlinger et al., 1999). Dietary factors, namely intake of fibre, fats, and vitamin D, may also play a role in the development of IBD (Del Pinto et al., 2015; Hou et al., 2011).

Treatment for IBD may include drugs such as steroids or biologics, diet therapy, or surgical intervention; a temporary ostomy may be created to allow bowel rest during a flare-up of disease (increased inflammation), or a person may receive a permanent ostomy so that diseased bowel can be removed (Fleshner, 2021a; Fleshner, 2021b; Hashash & Regueiro, 2021; Regueiro & Hashash, 2021). An ostomy may be created on an elective basis (e.g., a decision to manage chronic symptoms), or during an emergency (e.g., due to colonic perforation or gastrointestinal hemorrhaging) (Fleshner, 2021a; Fleshner, 2021b). Clinical features and regions affected vary by the subgroup of IBD.

2.2.2.1 Crohn's Disease. Crohn's disease can affect any area of the gastrointestinal tract, from the mouth to the perianal area (Peppercorn & Kane, 2021a). It involves transmural inflammation and may appear in varying areas of the gastrointestinal tract at the same time (discontinuous), with sections of healthy tissue between diseased areas (Peppercorn & Kane, 2021a).

2.2.2.2 Ulcerative Colitis. Unlike Crohn's disease, ulcerative colitis is limited to one area of the gastrointestinal tract (rectum and large intestine), and it is not transmural –

it only affects the mucosal layer of the colon. Also, it nearly always includes a diseased rectum and affects the colon in a continuous nature, meaning there are no sections of healthy colon between diseased areas (Peppercorn & Kane, 2021b).

2.2.3 Diverticular Disease

Diverticulosis is the presence of diverticula: sac-like protrusions of the wall of the colon; diverticular disease involves *symptomatic* diverticulosis due to issues such as diverticular bleeding, diverticulitis (inflammation of diverticula), or segmental colitis (Pemberton, 2021b). Approximately 25 percent of people with diverticulosis will experience diverticular disease, and it is estimated that more than 130,000 people are living with diverticular disease in Canada (Canadian Digestive Health Foundation, 2009; Dawson, 2016).

Diverticular disease is common in most industrialized countries, and primarily affects individuals ages 60 and above; however, incidence rates among the younger population have increased in recent years (Weizman & Nguyen, 2011). While age is still the primary risk factor, researchers have identified several lifestyle factors that may also contribute to increased risk, including low fibre intake, diets high in fat and/or red meat, low rates of physical activity, and high waist circumference (Pemberton, 2021b). People with diverticular disease may experience symptoms of constipation, diarrhea, nausea, vomiting, fever, and pain in the lower abdomen (commonly in the left lower quadrant; Pemberton, 2021c). Depending on the severity of the disease and the presence of complications, diverticular disease may be treated with antibiotics, intravenous fluids, pain medications, and/or surgery (which may include the creation of a temporary or permanent ileostomy or colostomy; Pemberton, 2020; Pemberton, 2021a).

2.3 Challenges for People Adapting to Life with an Ostomy

There are many aspects of adjusting to an ostomy that are common across the globe. The Ostomy Life Study, an online survey of people with ostomies across 11 countries, highlighted the everyday challenges of people living with an ostomy including issues related to leakage and ballooning, and how these challenges impact their day-to-day lives (Claessens et al., 2015). Participants of Claessens et al.'s study in 2015 indicated that worry of leakage caused them to limit their social activities (31%) or isolate themselves (12%); participants also worried that people would notice the appearance of their ostomy (43%) or smell an odour from their ostomy (34%). These findings indicate that living with an ostomy presents challenges that can cause changes in one's way of living and overall health and well-being.

Confidence of people with ostomies may increase over time but adjusting to life with an ostomy appears to be a longstanding issue. Thorpe and McArthur (2017) conducted interviews with 12 people at three, nine, and 15 months after the surgical creation of their intestinal ostomy to examine the experience of adapting to life with a stoma over time. Participants indicated that they were separated from their social environment by their post-operative symptoms during recovery and their ability to take part in routine activities of living. The amount of time it took to complete routine activities affected how quickly they felt able to participate in their social environment and their bodily confidence directly impacted their social self-confidence. Participants indicated that they feared caring for their stoma away from home and this prevented them from social participation, particularly early after their surgery, but some still experienced a lack of confidence at nine and 15 months. Participants in this study expressed the critical role of their partner in their acceptance of themselves. They identified their partner’s understanding and support as a crucial component of their acceptance and self-confidence, and without their understanding participants felt rejected and less confident. Family and friends were also identified as important sources of support when they were accepting of the ostomy and reassured the participant that having an ostomy was okay. This study highlights the ongoing need for support of individuals adjusting to life with an ostomy to enhance self-confidence and ostomy management.

Literature reviews of studies examining life with an ostomy indicate that getting an ostomy is associated with a negative impact on the person’s QOL (Brown, 2017; Di Gesaro, 2016). While QOL is a concern with any chronic illness, disease treatment that includes getting an ostomy can be particularly distressing and involves many physical and psychosocial changes. Researchers have found that rectal cancer survivors with an ostomy had a lower QOL, worse illness perceptions, and higher health care consumption than survivors who did not have an ostomy (Mols et al., 2014).

Additionally, researchers have indicated that experiences of men and women adjusting to life with a new ostomy may differ (Gautam & Poudel, 2016; Grant et al., 2011; Karabulut et al., 2014). Studies have shown that men score lower for adjustment on the Ostomy Adjustment Inventory-23 and the Psychosocial Adjustment to Illness Scale Self-Report (Gautam & Poudel, 2016; Karabulut et al., 2014). A cross-sectional study conducted in Nepal demonstrated that men reported more negative emotions and lower acceptance and social engagement scores in comparison to women (Gautam & Poudel, 2016). In Italy, a recent study by Giordano et al. (2020) found that women have better self-care maintenance and monitoring compared to men. Researchers have surmised that differences in gender experiences may be partially attributed to men’s desire for power and control, women’s acceptance of living with an ostomy (rather than seeing it as a challenge), or the higher capability of women to perform care (Gautam & Poudel, 2016; Karabulut et al., 2014). However, Grant et al. (2011) conducted a study using focus groups and found that women more frequently discussed difficulties sleeping, problems with body image, and experiences of depression, and studies of people with CRC indicate women are more vulnerable to distress (Laghousi et al., 2019; Tuinstra et al., 2004).

Aside from gender differences, few studies have reported demographic characteristics associated with adjustment to having an ostomy. Within studies from the United States, some researchers have conducted cross-sectional studies and reported that higher income is associated with better adjustment, better psychological well-being, and better health-related QOL (Horner et al., 2010; Lundy et al., 2009. Krouse et al., 2009). Bekkers et al., (1997) conducted a cohort study and followed patients who had a bowel resection with or without formation of a stoma and found that higher income had a significant positive effect on adaptation scores. In contrast, Scardillo et al., (2016) found no significant differences between income status and adaptation, but their study had a small sample size (n=48) and may have had insufficient power to detect differences.

Other factors such as education level, age, and comorbidity status may also impact a person’s ability to adapt to life with an ostomy, but more research is needed in this area. Giordano et al., (2020) conducted a longitudinal study and found that participants with higher levels of education had better self-care monitoring of their ostomy. Researchers have also demonstrated that the presence of comorbidities, particularly diabetes and conditions that affect sexual function, is associated with poorer health-related QOL and higher complication rates among patients, and that comorbidity status may have a greater affect on outcomes than age (Bosshardt, 2003; Krouse et al., 2009; Popek et al., 2010; Zelga et al., 2021).

2.4 Nutrition- and Food-Related Concerns of People with Ostomies

Nutrition- and food-related concerns of people with ostomies are not well known and are believed to be highly individualized (de Oliveira et al., 2018; Sun et al., 2014). Floruta (2001) discovered that while many people with ostomies said they do not adhere to a special diet long-term, the majority of people also stated that they continue to avoid some foods due to their ostomy, and the reason for doing so was commonly to minimize output and/or gas.

As one might expect, nutrition- and food-related concerns appear to vary by people with different types of ostomies; those with ileostomies tend to have more dietary concerns than those with colostomies (Richbourg, 2012). Foods that people with ostomies commonly report avoiding include nuts, cabbage, broccoli, raw vegetables, popcorn, and some stringy fruits such as oranges and pineapple; foods are commonly avoided in an effort to prevent output, leakage, gas, and/or odour (de Oliveira et al., 2018; Richbourg, 2012). Sun et al. (2014) investigated long-term concerns of people with ostomies due to CRC and found that in addition to restricting specific foods, participants reported changing the timing of their meals to control output and sometimes limiting or avoiding food consumption before leaving the house for a social outing or long-distance trip.

Complex factors play a role in the ability to adjust to life with an ostomy and experiences of diet changes are largely individualistic; people with ostomies have urged that people new to an ostomy should take a trial-and-error approach to diet (Floruta, 2001). Also, it seems that people with ostomies may not be content with current dietary approaches. For instance, Aronovitch et al. (2010) used a cross-sectional survey and found participants were poorly satisfied with lifestyle changes related to diet. Furthermore, in a pilot study exploring research priorities for ostomy-related QOL, participants stated that nutrition should be considered as a research priority (Hubbard et al., 2017). Although few studies have focused on a person's adjustment regarding food and nutrition after ostomy surgery, these research findings suggest that the eating experience and diet changes are important aspects of adjustment and more research is needed in this area.

2.5 Dietetic Counselling for People with Ostomies

Given the challenging adjustment process individuals experience with a new ostomy and the role that food and nutrition may have during this adjustment, it is important to examine the impact that dietetic counselling has on one's ability to adjust to life with an ostomy. However, dietetic practice guidelines for individuals living with ostomies have not been well established, and no research to date has explored the effectiveness of dietetic counselling for people with ostomies in Canada. Globally, there are few studies about dietetic counselling for people with ostomies. A small (n=28), observational study in Slovenia indicated that dietetic counselling may prevent inadvertent weight loss for people with high-output ileostomies (Jelenko & Kozjek, 2018). In contrast, a study conducted in the United Kingdom using semi-structured interviews indicated that dietary advice offered to people with ostomies was sometimes unhelpful, unrealistic, and incompatible with the individual's physiology, lifestyles, and food preferences (Morris & Leach, 2015).

Dietetic counselling can provide support for ostomy-related concerns previously described, such as avoiding high-fibre foods, delaying eating, preventing blockages, controlling odour and gas, preventing diarrhea and constipation, and maintaining adequate nutrition and hydration (Mahan et al., 2012; McDonough, 2013). Adjusting to life with an ostomy is complex and experiences vary between individuals, but many factors involved with adjustment may influence a person's diet and view of food (McDonough, 2013; Thorpe & McArthur, 2017).

2.6 Peer Ostomy Support Groups

Given the range of complex challenges that individuals with ostomies face, it is not surprising that peer support groups have been established for people with ostomies in several countries (Cross & Hottenstein, 2010; Lumdubwong et al., 2014; Ostomy Canada Society, 2022; Whiteley, 2019). The Ostomy Canada Society, a Canadian non-profit volunteer organization dedicated to supporting people with ostomies, has 60 peer support groups listed as active across Canada (Ostomy Canada Society, 2022). However, the benefits and effectiveness of peer support groups have not been thoroughly examined. Within Canada, research has not been conducted to examine characteristics of people who participate in support groups or the impact that attendance may have on adaptation or QOL. We used the term *support groups* to include both self-help and support groups as many support groups do not require leadership to be a person with lived experience, but many support groups do have such leaders through the nature of recruitment, and therefore, groups are not clearly categorized.

Within the current literature, some peer support groups for people with ostomies are limited to people diagnosed with cancer, which limits the generalizability of results.

For example, Lumdubwong et al., (2014) conducted a cross-sectional study in Thailand and found that there was no association between attendance of a support group for people with colorectal cancer and stress level. In the United States, peer support groups are more comparable to those in Canada (attendees have an ostomy for various bowel conditions), and anecdotal evidence from support group leaders underscores the potential benefits of these groups (Cross & Hottenstein, 2010). Byfield (2020), conducted semi-structured interviews with support group attendees and found that support groups provide hope and help attendees realize they are not alone, and provide opportunities for peers to relate to and learn from one another, which in turn, fosters independence. Researchers have also illustrated recruitment challenges due to only half of eligible patients in the United States being given support group information, and patients' increased use of technology to find health information (Miller, 2020; Schimmelpfenning, 2009). Preliminary research illustrates that web-based resources or telehealth-based ostomy self-management programs may be effective sources of support (Pittman et al., 2017; Weinstein et al., 2021).

2.7 Expanded Chronic Care Model

The Expanded Chronic Care Model (ECCM) was adapted from Wagner's Chronic Care Model and describes an approach to improving the health and well-being of people living with a chronic disease (Barr et al., 2003; Wagner, 1998). Creators of the ECCM recognized that people living with a chronic disease require comprehensive follow-up care to prevent worsening of symptoms and/or complications. The ECCM illustrates that the organization of the community, health care, and existing resources and policies influence the capacity for productive interactions between a proactive (interdisciplinary) team and the informed, activated patient to improve functional and health outcomes. The model suggests that quality of care can be improved through enhancing support for patients' self-management by increasing patients' confidence and personal skills, a sentiment echoed by researchers of ostomy care (Lopes & Decesaro, 2014). This thesis uses the ECCM to provide a conceptual framework to understand existing supports and to identify any areas where supports are missing for people with ostomies.

2.8 Availability of Dietetic Counselling in Newfoundland and Labrador

In Newfoundland and Labrador (NL), the majority of clinical dietitians are affiliated with hospitals and employed by regional health authorities. No current literature exists on this topic, and what we know in this area is from personal involvement in the health system and personal communications. While some dietitians may offer private practice, these services are not covered under provincial medical care insurance. Clinical dietitians affiliated with hospitals offer inpatient services and may offer outpatient services depending on the patient's diagnosis and geographic location. For example, in rural areas, services vary as dietitians often provide both inpatient and outpatient services from the hospital. In comparison, dietitians affiliated with hospitals within the metropolitan area of St. John's provide inpatient services only. Within St. John's, outpatient services offered by the regional health authority are limited to clinics that provide support to people specific diseases such as diabetes, kidney disease, and cancer. At the time of writing, there is less than one full-time-equivalent position allotted to care for "gastrointestinal diseases" in the St. John's area, and this dietitian is available at the Diabetes Education Centre (S. Smith, personal communication, July 3, 2022).

2.9 Conclusion

In summary, people undergo many changes after ostomy surgery, regardless of the diagnosis requiring the ostomy, the type of ostomy, or if the ostomy is permanent or not. People with ostomies may encounter challenges when managing their ostomy appliance and output such as leakage, ballooning, odour, or blockage, and they may also experience psychosocial concerns such as a change in body image, mental health, and/or QOL. However, very little is known about factors that may promote or inhibit adaptation to having an ostomy, such as income level, education, marital status, or the presence of comorbidities, particularly within the Canadian population.

In terms of diet-related concerns, the literature describes dietary management as an important aspect of ostomy management by restricting or incorporating particular foods and maintaining good nutrition and hydration status. Still, people with ostomies may not be content with current dietary approaches and their food-related concerns and experiences of dietetic counselling are not well understood. Further, dietetic literature is focused on the physical health of people with ostomies and does not discuss psychosocial elements of change. We have identified several gaps in current literature on this subject, including a lack of research within lived experience of having an ostomy by disease status, the role of support groups, models of care for people living with ostomies, person-centred dietetic counselling, and dietary interventions and counselling for people with ostomies. This thesis includes three studies and uses the ECCM to identify and describe how the organization of communities, health care, and existing resources and policies influence the health and well-being of people living with ostomies.

3.0 Qualitative Analysis of Data from r/ostomy

3.1 Introduction

For the first study, we[2] conducted a thematic analysis of Reddit (social media) posts made by people with ostomies which discussed food and nutrition. This study directly addresses research objective:

1. To describe the nutrition, food, and lifestyle-related concerns of people living with ostomies immediately after ostomy surgery and during ongoing self-management.

And indirectly addresses research objectives:

3. To describe the role of dietitians and their interactions within an interdisciplinary health care team to provide care to people with ostomies.
4. To describe the current practices of dietitians who counsel people with ostomies.
5. To describe patients' experiences of dietetic counselling.

Using social media data for health care research has increased over time (Chen et al., 2019). The internet has become widely used by patients to find information about their health conditions and treatment options and to be part of online support groups (Derksen et al., 2017). In turn, this has attracted the attention of health researchers who are interested to learn how patients are using social media during the management of their disease. An advantage of social media research is that large amounts of data are inexpensive and readily available to collect from various social media platforms (Chen et al., 2019).

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[2] Given that the nature of thematic analysis in qualitative research includes two or more team members reaching consensus, the pronoun "we" is used throughout this thesis. However, the pronoun "I" is used in places to denote work and processes conducted solely by myself, Lisa Blundell.

Reddit is a global social news network and discussion website. Reddit users exchange information and opinions through text, pictures, and links using pseudonyms. Niche forums, *subreddits*, are created within Reddit so that people can take part in conversations around a specific topic. Reddit users can author new posts and comment on existing posts; users can also *upvote* or *downvote* posts and add comments to show approval or disapproval, respectively.

The utilization of Reddit in health care research has increased in recent years, using various methods. For instance, researchers of mental health communities have used a Reddit archive and readability metrics to analyze communication characteristics between people with depression, bipolar disorder, and schizophrenia (Park & Conway, 2018). Food researchers have used Reddit's open-source application programming interface (API) and the Meaning Extraction Method (MEM) to identify the frequency of common words and phrases (Blackburn et al., 2018). Others have conducted content analyses of subreddit posts related to health issues such as eating disorders, e-cigarette use, and management of gout (Brett et al., 2019; Derksen et al., 2017; Sowles et al., 2018). Because Reddit users use pseudonyms to communicate with one another, posts may be more disinhibited compared to other social media platforms. This makes Reddit data particularly useful to explore stigmatized topics and capture candid thoughts and opinions that patients may feel less comfortable discussing in a health care setting.

3.2 Methods

In this study, we analyzed qualitative data from Reddit, specifically from the subreddit r/ostomy (Reddit Inc., 2021). These data included discussion posts and comments made by people who have an ostomy or who care for a person with an ostomy.

We specifically collected and analyzed the data that pertains to the food- and nutrition-related concerns of people with ostomies to better understand their eating experience and nutrition concerns.

3.2.1 Data Collection

Within Reddit, users have created a subreddit titled “ostomy” that is intended for “people with bags and those who love them,” (bags refer to ostomy appliances; Reddit Inc., 2021). Within this subreddit, users are typically people with ostomies or direct caregivers, and they discuss their experiences of living with an ostomy and exchange ostomy advice. To collect relevant data for analysis, we used R (an open-source software environment for statistical computing and graphics) and RStudio (software that makes R more user-friendly) to retrieve the data from the subreddit r/ostomy (The R Foundation, n.d.; Rstudio. 2018). Specifically, we used the *RedditExtractoR* package to retrieve posts and comments that included the following keywords: ate, blockage, breakfast, brunch, calorie, constipation, cook, diarrhea, diarrhoea, diet, dinner, drank, drink, eat, fat, fiber, fibre, fluid, food, gas, grocer, hydration, lunch, market, meal, nutrition, obstruction, odor, odour, protein, restaurant, smell, snack, supper, supplement, weight. The package was designed so that results would also include search terms if they were present as part of a larger word (e.g., the search terms diet and fiber included results for dietitian and Benefiber). The RedditExtractoR package was developed for use with R software by Ivan Rivera; we used the most recent version at the time of our data collection, dated May 5, 2009 (Rivera, 2021). In subreddits, users can create *posts* with content and a title, and users can comment on these posts. Together, these posts and comments create *threads*, and each thread can be thought of as a separate conversation. On May 29, 2020, we ran a search for posts containing each keyword listed above and extracted their corresponding threads, and then we combined each data set into one file. Therefore, the data were not limited to quotes that included these keywords specifically; the keyword(s) may have been presented anywhere within the conversation. Data were extracted from September 25, 2012, to May 28, 2020. There is a maximum amount of data that RedditExtractoR can extract, so data from r/ostomy from May 3, 2012 (when r/ostomy was created) to September 24, 2012, were not extracted. We then used the *dplyr* package to remove any duplicate threads and reformatted all dates to day-month-year for ease of use (Wickham, 2021).

Next, we converted the file to a comma-separated values (CSV) file to be viewed in Microsoft Excel and to analyze the data. We then removed any unnecessary variables collected by the RedditExtractoR package and used Microsoft headings to format each column (i.e., post title, post, author columns) using a different heading. We then converted the Microsoft Excel file to a Microsoft Word file; the various heading formats allowed us to view the titles of posts and Reddit usernames so we could follow the discussion easily because of consistent formatting (i.e., post titles were bolded, authors were in blue font, etc.). Next, we separated the Word file into 10 documents of 100 pages each for ease of use and imported these files into a qualitative data analysis program, namely Nvivo 12 (QSR International Pty Ltd.). We used Nvivo to auto-code by Microsoft headings so that each unique username was recognized as a *case* (unit of analysis).

3.2.2 Analysis

I analyzed each thread that was extracted, including the original post and all comments. An example post with comments is shown in Appendix A. All quotations are provided as written by the Reddit user and include several English dialects and English spellings. We made minor corrections for misspelled words and evident typing errors. Using inductive content analysis, my supervisor, Dr. Mathews, and I independently reviewed and coded a sample of approximately 100 pages of Reddit threads (approximately 10% of the data), and highlighted recurring words, concepts, and key themes we observed. We each made notes about our observations and emerging themes. We then met to compare and discuss individual coding templates and combined our individual codes through consensus. We described and defined each code and also described how codes related to each another until we reached agreement and created a final coding template (Green & Thorogood, 2018). Involving two independent coders increases the rigour and confirmability of findings (Given, 2008; Green & Thorogood, 2018). We used Nvivo software to analyze all of the extracted Reddit threads and group the data according to the final coding template.

I also kept a journal of field notes of my observations and thoughts during exploration of r/ostomy and throughout analysis to facilitate reflexivity (Atkinson, 2007; Hadi & Closs, 2016). My journal contained information about my observations about the Reddit data, the extraction process, my thoughts and perceptions, how codes related to one another, code similarities and differences, and general observations about specific groups within the data (i.e., people with recent surgeries versus those who have had an ostomy for many years). While individual codes were not changed, the grouping of some subthemes was modified based on observations noted in my journal and these were discussed with Dr. Mathews to ensure agreement. In addition to records of methodological information and in line with a pragmatic approach, my journal reflections were also focused on understanding experiences in the context of health care organization (particularly as it related to the role of dietitians) and highlighting actionable steps (Long et al., 2018).

Each Reddit user has a unique username that appears as their pseudonym on all their posts and comments (e.g., Lady_Marmalade21). As mentioned, each username was coded as a case in Nvivo which allowed us to document case *classifications*. (i.e., demographic information). We used Nvivo's classifications feature to record demographic characteristics of individual Reddit users based on information provided in their posts and comments (i.e., gender, age, type of ostomy, reason for ostomy, length of time with an ostomy). In the case of gender, some Reddit users explicitly noted their gender, while others alluded to their gender by their gender expression (e.g., username including "Mrs.") and description of gender norms (e.g., role as a father). Therefore, I recorded gender as either confirmed or assumed. If demographic characteristics for users were not discernable from their posts, we entered *unknown* for each variable. We used he/him pronouns for identified men and she/her pronouns for identified women. No other genders were identified in the data. If gender was unknown, we used they/them pronouns. User demographic data were summarized using frequencies and percentages. Each user was also assigned a unique identifier (four-digit code) to use in all reports and publications to prevent participant identification (e.g., R5287). Four-digit codes were generated using Microsoft Excel's RANDBETWEEN function.

To ensure trustworthiness and allow other researchers to assess transferability, I maintained an audit trail throughout the study by storing data files of the original data extracted, the cleaned data, and all versions of the coding template (dependability and confirmability), used thick quotes to code data (credibility), and described the context of each quote to ensure meaning was not misconstrued (credibility; Hadi & Closs, 2016; Kuper et al., 2008; Taylor et al., 2015).

3.3 Ethics

Under article 2.4 of the Tri-Council Policy Statement (TCPS2), this study did not require ethics review because it used publicly available information and there is no reasonable expectation of privacy (Government of Canada, 2018). Reddit is public and pseudonymous, meaning that users create a username and are not able to be identified unless they provide or post identifiable information voluntarily. To further protect the identities of individuals who use this subreddit, Reddit usernames were omitted from all study reports. In addition, I contacted the moderators of r/ostomy to inform them of my study and seek their approval, which they provided (Appendix B).

3.4 Results

I retrieved 4211 posts and comments from r/ostomy made by 853 unique Reddit users. Users varied in age, gender, diagnosis, ostomy type, and time spent living with their ostomy. Of the 853 users, I was able to discern the age of 87 individuals; more than half were under 40 years old (Table 3.1). I recorded gender for 118 individuals; 62 were confirmed or assumed as women, while 56 users were confirmed or assumed to be men.

Table 3.1

Summary of Demographic Data Available for Reddit Users (n=853)

Characteristics	n	Characteristics	n
Age		**Experience with ostomy**	
<20	5	Living with ileostomy	206
20-29	43	Living with colostomy	41
30-39	18	Living with an uncommon form of ostomy	12
40-49	12	Living with an ostomy (not specified)	242
50-59	6	Potentially undergoing ostomy surgery	18
60-69	2	Previously lived with an ostomy	38
70-79	1	Partner of a person with an ostomy	20
Unknown	767	Parent of a person with an ostomy	1
Gender		Child of a person living with an ostomy	8
Women (confirmed)	38	Health care provider	3
Women (assumed)	24	Unknown	352
Men (confirmed)	32	**Length of time having an ostomy**	
Men (assumed)	24	< 1 year	139
Unknown	735	1 or more years	114
Diagnosis		Unknown	600
CRC	25		
Ulcerative colitis	49		
Crohn's Disease	72		
IBD (unspecified)	7		
Diverticulitis	12		
Other	14		
Unknown	675		

Five hundred and one users had ostomies at the time of their discussion; 206 users had ileostomies and 242 stated they had an ostomy but did not specify what type. Twenty-nine users mentioned that they were a source of support for someone with an ostomy (i.e., partner, child, parent). We classified ostomies less than a year old as *new ostomies*, and those one or more years old as *long-term ostomies*. Of those who disclosed their length of time with an ostomy, approximately half of them had new ostomies. One hundred and seventy-eight people disclosed their diagnosis, 128 of which had a form of inflammatory bowel disease (Crohn’s disease or ulcerative colitis [IBD]), and 25 had colorectal cancer (CRC).

We identified five themes as recurring ideas present throughout the subreddit: Recovery and Adaptation, Management of Ostomy, Psychosocial Effects on Well-Being, Health Care Provider Interactions, and Peer Support (Table 3.2).

Table 3.2

Organization of Themes and Subthemes Within Reddit Study

First-Level Theme	Second-Level Theme	Third-Level Theme
Recovery and Adaptation	Changes in Quality of Life	
	Coming to Terms with Expectations	Preparedness Kits
	Struggle with Acceptance	
	Individuality of Experience	
Ostomy Management	Worries and Issues	Output Volume and Consistency
		Blockages
		Leaks
		Appliance Changes
		Gas and Odour
		Nutritional Status
	Management Techniques	Timing Eating and Fasting
		Food and Drink Choices
		Food Preparation and Portions
		Trial and Error
		Medications and Supplements
		Odour Control Products
Psychosocial Effects on Well-Being	Change in Body Image	Loss of Self-Esteem and Sense of Attractiveness
	Anxiety from Constant Vigilance	
	Loss and Grief	Anger and Injustice
		Incongruence with Expectations
		Unacceptance
	Change in Ability to Sleep	
	Mental and Physical Exhaustion	
	Suicidal Ideation	
Interactions with the Health System	Technical Knowledge vs. Lived Experience.	
	Overly Optimistic	
	Lack of Mental Health Support	
Peer Support		

3.4.1 Recovery and Adaptation

Throughout r/ostomy, the recurring theme of recovery and adaptation included discussion of the length of time it takes to recover from ostomy surgery, effects on quality of life (QOL), and acceptance of having an ostomy. The first year after surgery was frequently highlighted as a period of time needed for physical healing, mentally adapting, and learning to self-manage the appliance. User R4651 described the key challenges that take place in the first year after surgery: "*The first year is very hard for a lot of reasons. You have to find an appliance that works for you. You're in pain. You're embarrassed. You have frequent accidents that are very dehumanizing."* In line with advice from other long-term ostomies, user R8615 offered the following reassurance to a person who recently had ostomy surgery: "*My first year with an ostomy was difficult but as my body healed, my health, my physical strength and my outlook on life (and ultimately my condition) greatly improved as well.*" This theme has four subthemes: Changes in Quality of Life, Coming to Terms with Expectations, Struggle with Acceptance, and Individuality of Experience.

3.4.1.1 Changes in Quality of Life. In this study, many users commented on how their ostomy had impacted their day-to-day QOL and shared examples of their ability to participate in various activities and life events. For example, user R8843 shared how they feared life with an ileostomy, but was grateful for their new ability to do the things they enjoyed in life:

> *The thing that really hit me as a symbol of my life getting better was being able to go to the zoo with my son. That much time away from a bathroom or doing that much activity was impossible when you are constantly fighting Crohn's [disease] complications. I don't like my bag. it's impossible to completely hide under my clothes but I get to not miss work, go on family reunions.* (R8843)

Similarly, user R7847 (age 30-39) discussed how his ileostomy increased his ability to participate in meaningful moments of his life, specifically as a father and husband:

> *QOL for me has gone up a million percent. Best friends and wife admit I'm a totally different person. I was almost not there at all for the birth of [my] first child and was basically unable to help raise her until I had surgery. My wife was firmly against having a second [child] since I was almost no help. Now, she's more than willing to have another. I can go to parties, host parties, and since I'm not worried about how I feel at all, I can actually have conversations with people.* (R7847)

Prior to life with an ostomy, many Reddit users described they always relied on having washrooms nearby because of their disease symptoms. For some, having an ostomy meant less worry of urgently needing a washroom and therefore, they were more able to travel for work or leisure. User R5313 (age 40-49) described her change and newfound ability to go on long road trips:

> *Such a great feeling after years of bathroom anxiety related to my Crohn's [disease]. We used to go at the drop of a hat before I started to get ill. We drove over 800 miles this weekend, [...]. We only had to stop for the bathroom when I needed to pee or when we ate. We got a new teardrop camper and drove home, overnight was spent camped in a truck stop with no bathroom anxiety. I love road trips and not having to worry meant I got to enjoy how pretty the views are.* (R5313)

Similarly, user R6537 shared that her husband's ostomy allowed him to travel and enjoy times of leisure, without the constant anxiety of worrying about finding a washroom:

> *We went to BC this summer and I think that was eye-opening for him; we could leave in the morning where we previously couldn't leave until almost noon, we went to the beach and he wasn't searching for a public washroom the whole time and stressing about if he'd make it, he didn't feel too sick to want to do anything at any point. Whereas usually we'd have to cancel at least one activity we would have planned because that day would be the day he'd feel too sick to leave the hotel.* (R6537)

Contrary to those who experienced improvements in QOL, some users reported that their ostomy hindered their ability to participate in activities (e.g., exercise) and had negatively impacted their QOL. For example, one user posted:

> *I have to limit physical activity because after my first stoma, I went back to running (with my surgeon's go-ahead) and he is curious whether that caused some of my issue, so he wants me to be very careful. I am walking twice a day, though. I cannot meditate. My meditation was running, going to the gym, and baking. I can't do those anymore.* (R8423)

Often, this perspective coincided with reports of poor ostomy management – users with reduced QOL experienced issues such as appliance malfunction, high output, or pain, like user R1376, who had a new ileostomy due to his Crohn's disease.

> *The stoma is painful and what little QOL I had before is now gone completely. I spend my days now on disability leave from work, usually with an ice pack against my side, barely able to walk about or go to the bathroom [...]. My QOL that they said would be restored by getting rid of my colon and its pain has just been destroyed and the pain replaced with the stoma agony.* (R1376)

A perceived change in QOL was also dependent on a person's condition and symptom management before their ostomy. For example, R4227 had seen a substantial reduction in their symptoms after ostomy surgery:

> *I was miserable before, in pain, always puffy and irritable and depressed from long-term prednisone use. I was tired of trying medicine that ended up not working. I was exhausted always. Tired of going to the bathroom what seemed like a million times a day [...] I feel better now with my ostomy. I know a lot of people avoid the surgery, but I kind of embraced it because I felt so bad all the time.* (R4227)

In contrast, user R1515 could not relate to others who had been very sick before having an ostomy; she was diagnosed with familial adenomatous polyposis but had not felt sick before having her ileostomy, so her ostomy was seen as a burden, rather than a relief.

> *I find it hard to connect with most support groups and forums because the majority of people were sick and the bag is a blessing for them. Their QOL improved with it and they're happier now and unfortunately for me that's not the case. It's polar opposite for me going from being a healthy "normal" person to disabled and revolving my life around the bathroom. [...] I'm in the bathroom 10 times a day on average. I can't wear most of my clothes because they interfere*

> *with the bag due to placement. I always have to plan my bathroom breaks for outings even if it's just to the grocery store for supplies or for a walk with the dogs. All that on top of the healing process and it's hard to see the positives.* (R1515)

3.4.1.2 Coming to Terms with Expectations. Another common experience shared by Reddit users was coming to terms with expectations of life with an ostomy, meaning, while users may have predicted how their ostomy would work and how it would affect their life, they had to face the reality of their situation and learn to cope with it. A subtheme of Coming to Terms with Expectations is Preparedness Kits: many people coped with having an ostomy by preparing kits that had extra ostomy supplies, clothes, and anything they may need for their ostomy when they were away from home.

Sometimes ostomy issues (e.g., leaks) and complications made it difficult to come to terms with having an ostomy, but people tried to move on. For example, user R3305 had issues with their ostomy but slowly came to terms with the reality of their situation and learned to live with their ostomy (at least temporarily):

> *I hope to God I can get it reversed eventually but I've learned to make peace with it for the time being. […] there have been some issues with my ostomy and I had to learn some things the hard way on my own over the months.* (R3305)

Many users commented on how they prepared for an ostomy before they had their surgery by researching and reading about what to expect and how to manage an ostomy appliance. User R5166 (age 50-59) explained how their disease impacted their life before colostomy surgery, and how they had to accept that having fully functional bowels was not an option.

> *I had [my] colostomy surgery 4 weeks ago. It's not easy, still feel weak and still trying to figure out the perfect way to get [a] good seal. […] [Before surgery,] I took a few weeks to read and understand what I was up for. Finally decided I wanted my life back, wanted to be able to take long walks, go hiking, be able to*

> *walk to restaurants and just not have to plan my movements around access to a bathroom. I've had so many accidents over the years and spent so much time in bathrooms that I was totally fed up. I'm 58 [...] and felt like time was running out to enjoy life while I still could.* (R5166)

Many people with long-term ostomies offered reassurance, such as user R7676 who wrote, *"Accidents might happen in the beginning while you're working things out but you will become more in tune with your body as you go along."* User R4458 lived with a long-term ostomy and underscored the importance of patience when learning to cope with an ostomy and challenged others to think of their situation as a *new normal* and learn to adjust their expectations and enjoy life.

> *Everyone is different, and I certainly had my own issues coming to the point where I was comfortable with it, you just have to be patient and give it a bit of time. [...] I would give anything to be "normal" again, but then when I think about it, now I am normal. My current situation is my normal. So it is for you too. It's nobody's fault that you were diagnosed with [IBD], least of all yours. It's a tragedy that you now find yourself in your current situation, however it is now your new normal. You don't have to like it, but one way or another, you are going to deal with it. I am still upset inside about my own issues, but I learned to just get on with my life despite it all and stop feeling sorry for myself.* (R4458)

3.4.1.2.1 Preparedness Kits. Many users explained how a person with an ostomy has to be ready and anticipate having leaks and mishaps from time to time, and that the best way to be prepared was to carry a kit of ostomy supplies and extra clothes. For example, a person with a long-term ileostomy offered advice to people:

> "*Don't lose hope. You'll find a routine that works for you it will take a while but it'll happen. Carry an extra change with you, include paper towels and keep changes at your most visited places (I have one in my purse, backpack, boyfriend's house, and grandmother's) keep it in a Ziplock which will make disposal in a trash easier."* (R7750)

User R5313 suggested similar advice, with a detailed list of supplies as well as precautions to take in case of a leak during sleep:

> "*Get a mattress protector, waterproof kind, maybe 2 so you can apply a new one as needed. Leaks will happen. It is not a big thing. Don't beat yourself up Take spare clothes and a change kit, leaks will happen, don't stress. My kit has scissors, a cutting template, at least one bag and flange, duct tape, thickening powder, adhesive remover, plastic wastebasket liners and some small paper bags. Paper bags are to put my bagged waste into so no one has to see my waste. Carry a water bottle to drink from and one for bag rinses.*" (R5313)

Similarly, user R8678 shared how she copes with outings and time at work with her ostomy, and how she rarely has issues after learning what worked well for her:

> *Now I just carry a couple of precut pouches and disposal bags in my purse. I tend not to have issues anymore (7 years out). I take Imodium every day to keep my output more solid and the blowouts are less. I keep a second set of all my supplies at work too just in case I need to change.* (R8678)

3.4.1.3 Struggle with Acceptance. Reddit users described diverse experiences learning to accept their life with an ostomy. While some had accepted that their ostomy was a part of their life and did not see it as a barrier, others longed for a procedure that would remove their reliance on an ostomy or relieve their issues with their ostomy appliance. User R5219, a person with a long-term ostomy due to ulcerative colitis, reflected on their experience reconciling with their life changes due to an ostomy:

> *My output has always been high. [...] I realised it was something I tried to control, but I couldn't. In fact what I was doing was trying to regain control over an even bigger situation I had no choice in, which was ulcerative colitis and ending with a stoma bag. When I discovered this I just started accepting. My skin is dark, my hair is black, I'm tall, I like the colour grey, I like Lamborghini over Ferraris, I don't like pineapple on my pizza, I poop standing up and my output is high. It's just another that's mine.* (R5219)

User R2480 had also accepted their new normal, given that their new ostomy allows them to live life with fewer symptoms of their disease:

> *All I can say is it's honestly amazing how quickly it feels completely normal. I do however occasionally find myself having a flash moment when I suddenly think oh crap [...] how do I cope with this? Then I remember that this is 100% better than my life was 9 weeks ago. [...] I'm writing this in my garden, drinking a coffee and*

> *relaxing after having a beautiful, cooked breakfast. Before the bag I would have been in the toilet in agony unable to go outside.* (R2480)

People with long-term ostomies acknowledged they had not always been accepting of their ostomy, and it has taken some time to get used to it. User R2790 pointed out that they were embarrassed by their ostomy and appearance, but have learned to embrace it:

> *Getting an ostomy was almost freeing for me […] My new philosophy is that I'm just glad my body works in its [own] way and however my stomach looks, scarred up and lumpy, that was my doctor's work. Anyone with anything to say about my body or my shit bag can refer to my surgeon because I'm man-made now. Before I was like no! Don't look at my disgusting body! Now I'm like Feast your eyes on my lovely disgusting body!* (R2790)

However, acceptance was difficult for some who had ostomy surgery suddenly and unexpectedly, such as user R3217 who had emergency surgery due to (previously undiscovered) colon cancer. He wrote "*I'm so ready for this nightmare to be over. […] I have 10 weeks of chemo left, first chance I get I want it gone*." In contrast, user R7447 actively sought ostomy surgery to manage their symptoms and attributed their acceptance partially to their preparation for life with an ostomy before surgery.

> *I begged my Dr for surgery. I'm in my early 40s, extremely active and spent the last three years in [IBD] hell. I'm only about five weeks post-op but have not felt this good in so so long, I'm basically relieved. I guess [because] I researched and knew what I was getting into I was pretty accepting of my surgery. I have moments of course but so does everyone- ostomy or not.* (R7447)

The experience of having moments when an individual was not optimistic about life with an ostomy was common among Reddit users. User R5313 alluded to this experience by admitting she has not fully embraced her ostomy but is "mostly" fine with it two years post-surgery: "*I don't love my bag but I do love not writhing in pain as my bowel [is affected by] Crohn's disease. Mostly I am fine with the bag, death was not an* *option I was fine with.*" Feelings of hating their ostomy were sometimes triggered by appliance leaks, concerns over appearance, etc. User R6583, (age 20-29, one-month post-surgery), recounted an evening when they were completely overwhelmed with having an ileostomy after having several leaks:

> *Monday night for some reason everything just came crashing down, we were supposed to have a dinner party and I just couldn't do it. I just collapsed onto my bed (after changing my bag again) and wouldn't or couldn't get up. I couldn't find something nicer to wear than a hoodie that successfully hid my bag so I felt like it was constantly on display making me feel so self-conscious about it. Every time I thought about going out around everyone I started to cry and shake. I didn't trust my bag not to leak in front of everyone, I didn't want to eat dinner hoping that would prevent leaks. [...] Up till this point I hadn't cried or freaked out about all this, but last night it was like someone opened up the goddamn flood gates and every emotion possible flooded me.* (R6583)

3.4.1.4 Individuality of Experience. Overall, a persistent theme throughout the subreddit was the individuality of experience. Users detailed contradicting experiences of having an ostomy including differences between symptoms and issues, problematic foods, and preferred management techniques. For instance, user R7677 had complications that required her to stay in the hospital longer than most, "*Every person's post-op will be different! I have had friends who had a short 3-4 day stay, whereas I was in the hospital for 2 months with an additional surgery following my ostomy placement.*" When users offered advice or answered questions about living with an ostomy, they often cited that everyone's experience is different, and encouraged people to try new strategies, such as experimenting with different brands and types of ostomy appliances.

There was also a general agreement that different foods and diets worked well for different people, and there was no 'one-size-fits-all' list of foods for all people with an ostomy to avoid. Some Reddit users had little to no issues eating the foods they enjoyed, while others had frequent issues. User R5160 believed that no food was strictly off-limits and had no trouble with any foods they ate.

> *I tend to think most people worry too much about the things they can eat, the activities they can do, places they can travel [...] I would NEVER tell any ostomate that there are foods they have to avoid simply because everyone's opinion of what foods are safe is strictly their own. I have never encountered any issues with foods to the point that I say 'avoid this' or 'avoid that' but rather 'enjoy a little less of that next time.'* (R5160)

The majority of users agreed that diet and food choice was an individual experience for everyone. As user R7676 wrote, *"Working out what foods affect your tummy is something you work out as you go along. Everybody is different with or without a stoma so what might cause me problems may not be the same for you."* Some people did find it challenging to find the right diet regime for them because of their ostomy. For instance, R7916 wrote: "*I know some people who can eat whatever they want to eat with an ostomy. For me, that's not the case."* Further, recommended diets did not work for everyone. Many users commented that they felt like they were doing everything *right* and eating everything they *should*, but they could not manage their symptoms in the same way as others.

3.4.2 Ostomy Management

Reddit users regularly discussed self-management of their ostomy appliance and output, asked questions, and provided advice to one another. The goals of self-management were to have less disruption in their day-to-day activities, require fewer health care visits, and maintain their overall health. This theme is divided into two subthemes: Worries and Issues, and Management Techniques.

3.4.2.1 Worries and Issues. In this study, users cited frequent symptoms and concerns about living with an ostomy and their fear of issues such as leaks. People with a new ostomy tended to worry more about issues because they were unfamiliar with having an ostomy, were not sure what to expect, and did not know how to prevent and cope with issues. Worries and Issues has six subthemes, each describing common concerns: Output Volume and Consistency, Blockages, Leaks, Appliance Changes, Gas and Odour, and Nutritional Status.

3.4.2.1.1 Output Volume and Consistency. The consistency and volume of output were common concerns of Reddit users, particularly for people with ileostomies because their output tends to be more fluid, given that the colon (which reabsorbs water) is no longer involved in the digestive process in individuals with ileostomies. Having high output affected how much time was needed to manage their ostomy each day and contributed to dehydration. For example, user R7625 was frustrated by their lack of success to control the high output of their new ileostomy:

> *My output is WICKED high at 6 weeks out from surgery. [I] religiously log food, water intake, urine output and ostomy output. Have been on a very strict diet […]. My ostomy nurses are impressed with how good I'm eating. […] They boosted me from 8 tablets of Imodium a day to 8 tablets of Lomotil a day. 2 breakfast, lunch and dinner, and 2 before bed. Also eating Metamucil fiber thins, a pack first thing in the AM, at 3pm and before bed. Also trying Banana flakes on the specialist recommendation. All of these things have NOT worked to bring my output down [..]. It's hard to work and commute and visit buddies with it being so high [in volume].* (R7625)

Additionally, many people with ostomies wanted to prevent output from occurring at all when it was inconvenient. For example, user R5374 wanted to avoid having to tend to their ileostomy at work by manipulating how much they ate.

> *I'm 2 months post-op […] and I'm wondering what longer-term ostomates have on*

> *their lunch breaks? [...] It probably sounds stupid, but I just want to eat a packet of crisps and drink a protein milkshake - just to avoid having to go the bathroom multiple times while I'm working.* (R5374)

In terms of output consistency, users were concerned about their output being too liquid because liquid output was associated with dehydration and/or leakage. Liquid output was typically only a concern of people with ileostomies because people with colostomies tend to have well-formed stool. However, some people with colostomies experienced diarrhea, which was the case for user R6292 who was experiencing a flare-up of his Crohn's disease and leakage around his stoma.

> *I have a descending colostomy, have a bit of abdominal fat and my surgeon has made my ostomy sub-surface. Due to Crohn's flare-ups right now and my [stoma's position, my] output is quite liquid. The combination of these two doesn't allow the adhesive or paste to offer much protection and has resulted in painful wounds around the stoma.* (R6292)

3.4.2.1.2 Blockages. Another key concern of Reddit users was fear of intestinal blockages. Many users with new ostomies sought advice on how to prevent blockages and how to discern whether they were experiencing a blockage, such as user R7755 who was experiencing abnormalities in his ileostomy output: "*I'm scared – everything I read about blockages, this is a sign. I'm a little bloated but not much and don't have pain. I'm sorry if this is stupid, but I am new to this. Should I be worried?"* Generally, people were able to tolerate more foods without blockages once their stoma had healed and swelling went down, and blockages became less of a concern. People with colostomies were less likely to worry about blockages because colostomies are associated with a lower risk of blockages than ileostomies and they often present similarly to constipation rather than complete obstructions. Users experiencing potential blockages often turned to Reddit users to ask for advice. For example, user R7710 had a new ileostomy and posted:

> *I've possibly had a blockage a couple of weeks ago and maybe have one right now. I currently don't have any pain and don't think I've eaten anything new so far today, but my last output was sometime this morning and it had bits of undigested food in it. […] Does anyone know any remedies to help pass blockages?* (R7710)

3.4.2.1.3 Leaks. Reddit users were very concerned about leaks from their ostomy bag and frequently discussed their experience with leaks and asked others how leaks could be prevented. Users were most concerned with experiencing leaks while away from home or while in bed. User R6401 (age 30-39) described how despite all her efforts, leaks were still a concern.

> *I've been having leaking issues all week thanks to weight gain and changing post-radiation skin, but I thought I had things under control. [The leak] wasn't the end of the world but it was also super depressing to wake up covered in poo.* (R6401)

For many people, especially those with new ostomies, leaks were a concern because they were unpredictable and embarrassing.

> *My biggest fear [is] leaking at work or in class. […] My first night home from the hospital, me and my boyfriend were laying in bed and we smelt something really bad and he had asked if my bag was leaking and I didn't think it was but I got up to go to the bathroom and it spilt everywhere. My boyfriend and I have been together for several years and even have a child but I was still sooooo embarrassed!* (R4669)

Some users encountered difficulties getting a good seal of their appliance because of the shape of their stoma or the area around the stoma. Others had scars or hernias that they needed to workaround. It was common for users of r/ostomy to seek and give advice about leaks and ostomy products.

> *I need help. I'm new with an ileostomy, only a few months and my bag just. Keeps. Leaking. I have a big scar that is concave right next to where the bag adheres, […]. My husband has to cut away part of the bag's sticky part there so it won't go in the wound and so he can dress it. To try to keep it from leaking we've tried the paste, a belt, different bags, holding it down for the paste to dry, powder, […] and none of it works.* (R4667)

3.4.2.1.4 Appliance Changes. Another concern of users was wanting to control their output while they tried to change their ostomy bag so that they could have a convenient and successful bag change (changing their bag was easier when their stoma was not releasing waste). This was usually a concern of people with new ostomies who had not yet established a routine. Many users asked for advice and tips on how to have a successful appliance change. For example, user R9310 shared:

> *Today I did my first unsupervised bag change. [...] my stoma leaked liquid and poo almost constantly, to the point I was afraid I couldn't get my wafer on quick enough without the adhesive getting wet with output and not sticking. Since I am new to this I know it should get better and easier, especially as my output gets a little more predictable but in the meantime, I was wondering what other people do during bag changes when it just seems like the output won't stop long enough to do anything.* (R9310)

3.4.2.1.5 Gas and Odour. Gas and odour were frequent concerns of ostomy management. Many people sought advice to prevent gas and odour because they were concerned about others noticing their ostomy (i.e., from ballooning, noise, or odour).

> *Do you guys have any advice to help with the amount of gas in my bag? I rarely drink pop or carbonated food. I've recently gotten into a new relationship and although he knows about my bag it's still embarrassing to explain everything to him.* (R3529)

People with a new ostomy asked how much odour was normal and sought advice on how other people dealt with odour. Users stated that odour typically became more manageable after recovery from surgery and consuming a regular diet. Sometimes, users explained that odour became problematic even after establishing a routine.

> *I can go a week [with the same appliance] with no problems. Haven't needed to worry about a smell until yesterday, and today it is really bad. [...] I just changed it on Sunday. Took a shower and rinsed the pouch yesterday but it is back today. I can't think of anything I've eaten that's different.* (R7403)

Users were also concerned that ballooning may cause a leak – particularly overnight. For example, user R4191 described their concern with their new ileostomy:

> *My most common issue is probably the fear of leaking because of gas filling up the bag, and the stool pushing its way out. I find I'm burping my bag quite a bit. It's mostly a problem in the mornings when the gas builds up overnight. If I oversleep I'm in danger of the gas pushing the ring open and letting stool leak out. Sometimes I'll wake up if it's uncomfortable enough and I'll empty or burp the bag.* (R4191)

3.4.2.1.6 Nutritional Status. Another common concern discussed was nutritional status, including specific nutrient absorption, vitamin and mineral supplementation, hydration, and weight changes. Nutrient absorption was a concern for users because they worried about how their shortened gastrointestinal tract affected transit time. Specifically, vitamin B12 was a common vitamin of concern, because of its unique absorption process. It is absorbed in the ileum of the small intestine and many users were advising B12 supplementation for people with ileostomies, particularly for those who had part of the ileum removed. User R6929 shared their concern about transit time and absorption.

> *I am always concerned about properly absorbing the needed nutrients from my meals. I am very conscious about what I eat and I keep my diet very healthy as well [and] drink plenty of water [...]. For me, it takes roughly 12 hours for a meal to make into the [ileostomy] bag (sorry to be graphic) and I am wondering if this is a normal transit time through the system or if I need to do something to increase the time my body has to absorb everything it can. Has anyone had any issues with nutritional deficits or anything of the like?* (R6929)

User R2374 also had an ileostomy and was concerned that their transit was fast based on the consistency of their output, leading to malabsorption and weight loss, despite their attempt to stay nourished by changing their diet.

> *It [has] been two years and I still struggle with maintaining solid output. I need some help figuring out a suitable diet [...]. On top of the less than solid output, I can't stay hydrated to save my life and I can't keep weight on me. I feel like nothing I eat gets absorbed. Tried googling some guides but they all said the same*

> *thing. Toast, bananas, rice, and applesauce*. (R2374)

Some Reddit users struggled with weight loss and felt that diet changes alone were not enough and contemplated parenteral nutrition (nutrition delivered intravenously).

> *I've been struggling with maintaining a somewhat normal weight since I had my surgery almost 2 years ago […]. I'm severely underweight, I know that and want to be healthy. I saw a new nutritionist last week who diagnosed me as anorexic but that it was medically induced. […] I've asked for a port [intravenous catheter] to help with hydration but now I'm going to ask for it to help with nutrition.* (R5266)

Conversely, others had experienced such an improvement in absorption that they had gained weight and were sometimes looking for weight *loss*. For example, user R4365 (age 20-29) had substantial weight gain after acquiring her ileostomy:

> *I gained almost 1kg (2.2lb) per day for the first week, then down to 500gm per day (1.1lb) for the next few weeks. I found for me it was due to [eating during recovery and] finally having the ability to digest well. As my eating leveled out I stopped gaining so quickly. Since my surgery 6 months ago I've gained around 18kg (39.7lb).* (R4365)

Many users explained that their disease was better managed with an ostomy, which contributed to electrolyte balance. For example, user R4365 (person with a new ileostomy) wrote "*my blood tests are completely normal for the first time in over a decade so I'm clearly actually absorbing my food.*"

Overall, there was a diversity of experiences, but a common observation was the frustration described by Reddit users when trying to manage their symptoms and stay well-nourished. For instance, user R8423 summed up their experience in the weeks following their ileostomy surgery by saying, "*Food is a nightmare. I am now sticking to Chex, crackers, protein shakes and calorie drinks, and non-dairy ice cream. Literally just to get calories. […] I haven't had proper nutrition in probably months.*"

The other key concern regarding nutritional status was hydration and electrolyte balance. Hydration was a long-term concern, meaning that both people with new ostomies and long-term ostomies expressed concern and regularly monitored themselves for signs of dehydration. As user R4458 said, "*Hydration is the single most important thing*." Many users had experienced dehydration, and some required intravenous fluids and hospitalization. For example, user R8423 said, "*I was recently admitted [to the hospital] for dehydration, too. New ileostomate. It's no joke. My sodium went so low that they said I could have a seizure at any minute.*"

3.4.2.2 Management Techniques.

Throughout r/ostomy, there was a frequent discussion of how to control or manipulate ostomy output, usually to have safe, predictable, healthy, and/or convenient output. This theme has six subthemes: Timing Eating and Fasting, Food and Drink Choices, Food Preparation and Portions, Trial and Error, Medications and Supplements, and Odour Control Products.

3.4.2.2.1 Timing Eating and Fasting.

Users described management strategies that involved fasting and/or timing when a person eats in order to control output. For example, user R2235 tried to adhere to a strict schedule to have regular output and had each meal and snack timed so that the bag could be emptied at regular intervals.

> *I can say that this method [of eating regularly] works for me. But things can sometimes get out of hand. When I eat too much of green things, or too much pasta, the output changes. Sometimes I start to get hungry around 10 or something, and my mind turns to food, and the stomach knows it, that bastard, and it turns on the churn and my bag fills up way sooner than I would like.* (R2235)

Other people avoided foods at specific times to control the amount of output they had *overnight* because they usually had difficulty sleeping and were worried about leaks or they had to get up to empty their ostomy bag throughout the night. Some people, such as user R7916, contemplated skipping a meal altogether to be able to sleep at night.

> *The best way to avoid walking up as much is by not eating too late in the evening. I try to stop eating by 6 or 7 pm and I still wake up 1-3 times a night. Maybe if I transitioned to just eating breakfast and lunch I would be able to sleep a full night.* (R7916)

Some users fasted for extended periods in an effort to prepare for an appliance change. User R1376 used this strategy but thought it may have contributed to weight loss:

> *When I want to change the appliance, I have to fast myself completely at least a good 10-12 hours in advance just to have a hope [that] the next day that I can shower and change out the barrier without the stoma spitting up waste (which it still often does). […] I went from 263lbs to about 205 where I am now.* (R1376)

User R4065's advice to people with new ostomies learning to change their appliance was:

> *Pick the time more strategically (which will require figuring out the schedule of how fast food moves through her system). I have an ileostomy, but the issue is still the same -- if I try and change my adhesive in the afternoon after I've already eaten, I'm asking for trouble! For me it works best about an hour after I've woken up, but before I've eaten/drank anything (except water).* (R4065)

However, others had accepted that controlling their output to change their bag was difficult, if not impossible, and gave up on trying to control it by their eating schedule, such as user R1041, who had an ileostomy due to CRC.

> *Changing the bag was always dicey because I never figured out a great eating/changing the bag schedule, so sometimes my stoma would poop while I was changing the bag. Clean again, wipe again, poop some more. And again. Sometimes many times.* (R1041)

3.4.2.2.2 Food and Drink Choices. A frequent management technique used by Reddit users was purposefully to avoid or purposefully consume specific foods or drinks to address their concerns. For example, many users restricted their diet immediately after surgery and avoided foods that they feared may cause a blockage or other issues. Common foods discussed to avoid included: high-fibre grains, raw vegetables, raw fruits (skins in particular), nuts, mushrooms, corn, and popcorn. After avoiding such foods for two years, user R2886 was hoping they could expand their diet.

> *I had my [surgery] in March 2016 and since then I have practically avoided all things that might cause intestinal blockages (cabbage, pineapple, bean sprouts, tomato skins, nuts, coconuts, lettuce, celery, popcorn, mushrooms and dried fruit) I just want to gauge [what others eat] so I can start eating healthier. I'm looking to implement more lean meals, vegetables, and fruits.* (R2886)

Users also discussed avoiding some foods and drinks that were likely to cause gas or odour, such as carbonated beverages, cruciferous vegetables, or fish. For example, user R8028 stated, *"don't chew gum, avoid using a straw, try to avoid milk products and stay away from the veggies that can cause [gas] (broccoli, cauliflower, Brussel sprouts, etc)."*

Some people explained how food choice could also prevent or cause leaks by causing their output to be mostly liquid or to be so thick that it clogs the flow of output in the bag and puts pressure on the flange. For example, user R9744 described his experience with ileostomy leaks based on his food choice:

> *I've noticed that this is HIGHLY correlated with my diet. If I'm "clogged up" and only have liquid output, or if I've only had coffee and liquid all day, then the chance of leaks is almost certain. If I eat well and have consistent output then there is usually no problem.* (R9744)

Reddit users commonly discussed eating foods to thicken output such as peanut butter, marshmallows, and foods with soluble fibre, such as applesauce. User R6901 described how weight management and output consistency was a delicate balance at times as a woman with a new ileostomy:

> *Unfortunately, most of the foods that thicken your output are also high in carbs. But, yeah, weight gain has been a huge problem for me three years down the road. In my case, being an older woman doesn't help either, due to the metabolism basically shutting down once you turn 50, LOL. […]. Things like unsweetened applesauce will thicken output without adding a lot of calories.* (R6901)

Dietary fibre was a frequent topic of discussion when considering food choices. Many users reported being told to avoid high-fibre foods for about six weeks post-surgery. Fibre continued to be a key aspect of managing output for people long-term. User R9930 elaborated on the different sources of fibre and fibre's effect on their ileostomy output:

> *Fiber is also a really important part of this - insoluble fiber can cause water to release into the gut and make output watery, but soluble fiber can actually be beneficial, and help make things more regular [...] some soft soluble fiber might might help your system naturally regulate some water content. For soft soluble fiber I eat ripe bananas, applesauce, cantaloupe and cooked zucchini. If I pair one of these things with plain white rice, I can usually get my output to thicken up.* (R9930)

The majority of people with long-term ostomies typically reported eating a large variety of foods and being less restrictive over time. User R7167 tried to reassure others that they could be less restrictive over time:

> *I basically eat everything. For the first month or so, I [ate] low residue [foods] like white breads, no fibrous food. I've had my stoma for 2 years now and I'm able to eat raw veggies, mushrooms, raw fruits, seeds. You name it. The only thing I stay away from is popcorn. [...] Make sure you chew it very well and once you understand how your body reacts to it, you can progress slowly.* (R7167)

There were also very diverse opinions on how to manage electrolytes and prevent dehydration. Some users promoted drinking water only, some consumed sports drinks, while some advised drinking isotonic solutions. User R2948 wrote "*...nothing that can beat plain Jane water. Normies [people without ostomies] can get away with juices and sports drinks, but our guts have a really hard time absorbing liquids from surgery drinks.*" Meanwhile, user R1312 said "*Pro tip: if you feel dehydrated sugary drinks will hydrate you more as the glucose helps get it into the blood faster. So Gatorade etc."* User R9807 offered different advice and suggested an isotonic beverage:

> *Lucozade [...] or Gatorade [have electrolytes] but generally have way less salt*

> *[than] a classic isotonic. You can find recipes online that you can make at home! They help immensely with keeping hydrated. Drinking loads and loads of water can sometimes just make the problem worse!* (R9807)

3.4.2.2.3 Food Preparation and Portions. Another management technique related to diet involved preparing food in particular ways to aid in digestion (e.g., cooking vegetables until soft), and/or managing food portion sizes. The advice of many people with long-term ostomies to people with new ostomies was to eat smaller portions during meals at first and always chew well. User R6401 summarized her strategies in the hopes of helping people cope with their new ostomy:

> *The biggest thing for me, other than hydration and really making sure that I chew things [well], has been changing how I prepare my food. [...] Things like pepper skins and raw carrots tend to go through me whole, so I make them tiny. [...] I also steam my veggies for about thirty seconds longer than I want to, because having them a wee bit softer also makes for less gas and easier digestion.* (R6401)

Users also advised not to eat large portions of foods that may cause a blockage when consumed in large quantities (e.g., nuts), and to eat small amounts when reintroducing high-risk foods such as popcorn.

> *Chew it [very well and] only give yourself a small portion to start and work your way up, don't eat it from the bag or get a large [popcorn] at the movies [...], and drink tons of water, even more than usual.* (R2773)

As mentioned, some Reddit users cited weight gain as a concern since acquiring an ostomy. Suggestions for weight control included calorie counting, low-carb diets, portion control, and specific diet regimes (e.g., keto diet). For example, user R6955 had a new ileostomy and gave the following advice:

> *I would focus on calorie counting. [...] You might have to eat a little less than you are used to now that your body is absorbing everything. After my surgery, I definitely went a little heavy on the calories since I wanted to gain a little weight but now I'm having to cut my portions a bit.* (R6955)

3.4.2.2.4 Trial and Error. Users described how managing an ostomy and controlling output involved trial and error. People experimented with various ostomy supplies, water consumption, and food intake. User R9548 described that learning what to expect of output took time and experimenting with diet.

> *It is a lot of learning. A lot of experimenting. You eat or drink something and it's either a yes or a no. And you have to take that risk that it might not work. But you won't know until you try something.* (R9548)

A key factor in managing leaks was the choice and application of the ostomy appliance. Most of the discussions around leaks were about trying different ostomy bag brands, sizes, barrier rings, and applying the bag with a good seal, sometimes by using heat. Reddit users discussed how trial and error helped them find a method that worked and increased their confidence that their ostomy would not leak.

> *After many months of trial and error [I have a] method I now use to apply my ostomy, that now gives me a comfortable level of confidence that my ostomy will likely not leak, and I'm a happier person for it.* (R3305)

As illustrated above, once users had found their preferred dietary habits, ostomy products, and methods of applying their ostomy bag to their stoma, they felt more confident overall and were more likely to take part in regular activities outside of their homes. User R1401 empathized with people who experienced ostomy leaks frequently, and shared their experiences with an ileostomy to offer encouragement to keep trying different products:

> *I tried different bags, 1 piece, two-piece, Hollister, Coloplast. Convex, not convex. Finally I hit on the right one and it was like the heavens opened up and poo rained down no more. It was a magical moment. Once it all got situated I felt more like venturing out of the house.* (R1401)

3.4.2.2.5 Medications and Supplements.

Reddit users described management strategies involving the consumption of supplements or medication to affect ostomy output or combat ostomy-related issues (i.e., poor nutritional status). Many Reddit users consumed fibre supplements or medication (i.e., loperamide) to slow and thicken ostomy output. Several users consumed Benefiber or Metamucil, but people had mixed success; some people relied on them regularly, while others said they made the situation worse. Users usually had success with loperamide, but many needed high doses.

> *I tend to take 3 Loperamide a day, and that keeps things fairly regular with me emptying around 4 or 5 times a day […]. Some odd days I get really watery output but I just take a double dose of some Loperamide and eat plain things and it sorts itself out.* (R4547)

Users also cited taking other medications such as bisacodyl, Lotomil, polycarbophil, EnteraGam, or codeine to slow and thicken output.

Several users also reported taking multivitamins and/or drinking nutrition shakes to improve their nutritional status. Many advised others to frequently request bloodwork to detect any vitamin or mineral deficiencies, such as user R2672: "*[Get] your blood work done to determine your numbers and start taking easy melt supplements. You need calcium, and vitamin D, B12 and iron, maybe a biotin supplemental easy melt tablet*."

3.4.2.2.6 Odour Control Products. Instead of manipulating diet to *prevent* odour, some people suggested *masking* odour by using appliances with a filter, putting mints in their bag, or buying products like odour control drops or odour control sachets to put in their bag. For example, user R9249 offered reassurance and advice to people with new ostomies:

> *The smell fades after surgery. Especially since you may not be eating as much as usual post-op […] Once you are eating regularly it gets much more tolerable. Otherwise, I use [toilet spray] and spray in the toilet before emptying and put deodorant drops in after every empty. Some drops work better for different people,*

so experiment. (R9249)

Many users suggested trying a product called ConvaTec Diamonds, which are gelling and odour control sachets, or Hollister's m9 Odor Eliminator (spray or drops). Others were concerned about the cost of using such products and placed a mint in their ostomy bag, which they viewed as equally effective. Some people carried a scented spray with them to use in workplace or public washrooms. Reddit users also explained how most ostomy bags have filters that work well, and people with long-term ostomies were less concerned with odour.

3.4.3 Psychosocial Effects on Well-Being

Reddit users described the psychosocial impact of acquiring an ostomy. Psychosocial impact was not a direct result of ostomy surgery; these effects stemmed from the physical changes that cause emotional and mental health concerns for an individual's well-being. For Reddit users, having an ostomy often altered one's thoughts and behaviours due to changes in their physical appearance, the time and effort involved with self-management, the experience of unwanted symptoms, and differences in abilities or needs. In turn, these changes affected how Reddit users participated or interacted in social activities, work settings, or family settings, and often made impacted their mental health. This theme has seven subthemes: Change in Body Image, Anxiety from Constant Vigilance, Loss and Grief, Change in Ability to Sleep, Anger and Injustice, Mental and Physical Exhaustion, and Suicidal Ideation.

3.4.3.1 Change in Body Image. Reddit users discussed how their ostomy affected their physical appearance and their thoughts and perceptions of their bodies and how changes in body image affected users' confidence and sense of attractiveness in romantic and sexual relationships.

Body image changes from having an ostomy were in addition to previous changes caused by medical treatment, such as steroid treatment and other surgeries. User R2004 described how her new ostomy and scars caused her to feel 'ugly', her feelings were triggered by an unexpected leak from her appliance:

> *I changed my bag this morning by myself for the first time, but it opened a bit, so I had to change it again. I feel so ugly. My boyfriend works in [the] medical [field], but in his words, It's still poop. I have so many steroid scars - huge stretch marks all down my stomach, arms, thighs, and back - and now I have these scars too.* (R2004)

Several users mentioned how they feel less beautiful since acquiring an ostomy. The thought of wearing swimwear often caused anxiety. Sometimes a person's worry regarding a change in appearance was compounded by their expectations of beauty at their age. This was the case for R5047, a 25-year-old woman with an ostomy who wrote "*I hate feeling so alienated from other people my age. Even stupid stuff like not wanting to wear a bikini*." User R4365 shared this sentiment, but she had learned how to cope:

> *I was scared of the destruction of my bikini body. As a 27-year-old I feel like I'm still entitled to a little vanity. I was adamant that I'd never swim in public again, but after trying on different one-piece styles I found swimwear that allows me to still feel young and hot while covering up my secrets.* (R4365)

Several Reddit users shared tips about how to manage their appearance with an ostomy so they could feel better about their appearance. Some people wore loose-fitting clothes, long shirts, high-waisted pants or skirts, opaque bags or ostomy bag covers, or an ostomy belt to conceal their appliance. Reddit users coped somewhat differently depending on the location of their stoma and their preference. For example, user R7104 said “*I always wear mine inside my pants. And no one has ever noticed I have an ostomy. Most people don’t believe me when I do tell them.*” Whereas user R2589 commented “*I just wear long shirts. I never liked tucking the bag into my pants. I sometimes tape up the bottom of the pouch so it doesn't stick out below my shirt.*” Many people had learned how to cope with the concern of appearance, and it was no longer a worry.

> *I was scared about how visible it would be, especially given that I often wear tight clothes. This is a non-issue, with an elastic hernia prevention belt I can wear skin-tight clothes and you wouldn't know I had [a] stoma unless you touched the right spot to feel the firmness of the flange.* (R4365)

3.4.3.1.1 Loss of Self-Esteem and Sense of Attractiveness.

Changes in physical appearance and body image affected people’s self-confidence and sense of attractiveness, particularly in romantic and sexual relationships. For instance, user R9723 (age 20-29) had previously had a colostomy, but years after its reversal she was facing the possibility of having an ileostomy; she described her worry that an ileostomy would further affect her self-esteem and sexuality:

> *I have a tragic self-esteem which shines through in our sexual relationship and I'm worried this [ileostomy] is going to affect it even more. [...] Sadly and unhappily, my stomach is already heavily scarred, lumpy and has [a] loss of sensation in small areas from previous surgeries [...]. I definitely don't want to be ashamed and hide it away at all. [...] But a bag can be confronting for people not used to it.* (R9723)

While many people expressed similar concerns, a sense of worry was particularly prominent among single people considering dating or engaging in a new partnership. User R3127 commented, “*Another thing I can never imagine being able to meet a woman and her actually wanting to have sex with me when I have a bag of shit hanging off of me*.” User R8268, while not actively pursuing a relationship at the time, commented on how she would try to conceal her ostomy during the early stages of dating and how it hindered her from feeling confident and feminine:

> *I had a serious relationship end in [February] and haven't even entertained the idea of dating since, so the bag has not come up as an issue with a partner yet, but I have no idea how it will be when I eventually do have a relationship. Luckily the Sensura Mio bags are grey, fold up, and just kind of nicer(?) somehow. So I'm not too concerned with it, since I assume I will just wear a band to cover it or something at first or maybe a long t-shirt. I don't know. I'll cross that bridge when I come to it, lol. Still hard to feel feminine and attractive even with the bag underneath clothing, though.* (R8268)

Changes in body image and confidence led user R2082 (age 30-39) to consider another surgery to have his ileostomy reversed and a j-pouch created so that he could feel more attractive:

> *I was confident in college, slightly cocky even but that was all gone now. […] [After surgery] my own problems with my body image, coming to terms with the ileostomy prevented me from seriously pursuing relationships because I don't consider myself 'sexy' and often thought that any girl interested in me could do better. And so here I am, revisiting an old topic: Should I try an internal pouch. On the plus side, it should help me with my body image issues, apart from a few scars there won't be anything to hide anymore.* (R2082)

Some users tried to reassure people with new ostomies that they would find a romantic/sexual partner who was not deterred by their ostomy. User R8274 (age 20-29) wrote in response to user R2082’s post (above):

> *Any woman who is worth your time and actually into you will be totally unflustered by the fact that you wear an appliance. Soon after I had my permanent ileostomy I got into a long-term relationship and thought for a long time that I'd just been fantastically lucky to stumble across a woman who could tolerate my weird body. Nothing could have been further from the truth. Since that relationship ended I've done a lot of dating and even had some one-night stands and the ileostomy has not been an issue even once. It gets very easy with practice to find a simple explanation for what it is and why it's there.* (R8274)

Partners of people with ostomies also offered reassurance to people with new ostomies by commenting how they loved their partner and were happy they were alive and well.

> *I just wanted to reassure you there are people out there who will not care. My*

> *husband just had the surgery […]. I [love him] and he's worth all the awkward or uncomfortable bits. Truth is, when you're with someone there's always going to be parts of life that are messy, no one escapes without bad happening at some point. The right girl will be there to weather any storm with you and the bag really isn't a huge deal in the grand scheme of things.* (R6537)

3.4.3.2 Anxiety from Constant Vigilance. Reddit users described frequent experiences of anxiety caused by constantly monitoring their ostomy and fear of ostomy dysfunction, and described how their anxiety affected their day-to-day activities. People with ostomies commented on feeling the need to be prepared for anything and everything related to their ostomy and the related stress, which caused them to limit how often they left their homes to do things that used to be less stressful (e.g., go out to eat with friends, travel, etc.). For instance, user R3305 highlighted the constant worry of their ostomy leaking, and how anxiety affected their ability to socialize.

> *The primary issue I've faced was the constant anxiety and worry of leakage and how it always interjected itself in how I live my life. Would I be in my car? At a restaurant? With friends? Asleep? The answer is yes, all those scenarios and more. I got to where I didn't want to leave the house because of the risk. I've had tons of unfortunate, embarrassing experiences which I want to save you from experiencing.* (R3305)

Similarly, despite frequent socialization, user R9249 described how her ileostomy ruined the enjoyment that should come from being with others because she worried about leaks.

> *I have so much anxiety about it [leaking] that it basically has me unable to leave home and enjoy myself much. Lunches with friends should be fun, but they are an exercise in panic, because I am obsessed with if I am leaking, or how full my bag is since it fills up very quickly while eating. I become so terrified that my blood pressure skyrockets and I find myself drenched with sweat, and unable to even enjoy my meal.* (R9249)

Travelling was particularly worrisome for people with an ostomy and caused anxiety during road trips and flights for business or vacation. User R5228 (long-term ostomy) discussed their struggle to travel by plane, "*For me, airports and airplanes are the worst.*

I'm naturally an anxious person… I find that anxious sweat - which I get a lot of - seems to make my flange unstick faster than anything else."

Some of those who experienced anxiety described how the constant vigilance was mentally taxing and how it has taken a toll on their lives. User R1376 (age 40-49) discussed the toll his new ileostomy had on his mental health and his relentless worrying:

> *I have a constant terror and paranoia to check out and watch my pouches and barriers for leaks. I sleep only a couple hours a night. I don't dare wear my CPAP or take sleep aids because I don't want to fall asleep so deeply that I sleep through another leak. I'm slowly going nuts racking up the massive sleep debt. I don't go out. I can't exercise. I eat but most of the time very little because of nausea… All day I am in my house. Checking my bag. Checking the barrier. Constantly feeling the stoma move or the waste going into the bag.* (R1376)

Overall, people with new ostomies were commonly very stressed about how to work, eat, socialize, and sleep when a leak or appliance dysfunction could occur. In contrast, people with long-term ostomies (greater than one year) usually appeared more relaxed about continuing life activities and equipped to deal with any leaks if they did occur.

3.4.3.3 Loss and Grief. Users described the impact of having been affected by illness and needing frequent health care, causing a person to grieve the loss of life's normalities without illness. Often, users had a history of complications during surgery or other adverse effects from treatments that caused a loss of time in their lives - their time was spent in hospital and recovering from illness rather than their normal day-to-day activities. Users also often mentioned their age – juxta positioning their youth to their experiences of living a different life than they perhaps wanted for themselves, grieving years of life they have lost. User R1131 encouraged others to allow themselves to grieve their normal life:

It isn't easy. […] But as one therapist told me, there can be a huge gap between

> *what is most ideal, and harsh reality, and the bigger the gap, the greater the distress. Allowing yourself to experience the grief and getting to know your stoma will bring you closer to acceptance.* (R1131)

Some people described the ‘ups and downs’ of grappling with life with an ostomy, moving between feelings of positivity, frustration, and sadness. For example, R6537 referred to her experience as a “rollercoaster” and described how her illness deprived her of normalcy. She explained how she leaned into her emotions when necessary:

> *Health-status rollercoaster fatigue is so real. I just got my ostomy, a colostomy, two weeks ago. I've had severe Crohn's for 27 years […]. I'd thought that when I was finally a mother I would be able to somehow earn a little peace and enjoy motherhood and co-parenting with my amazingly supportive, beautiful human being of a husband. But of course, that's not how autoimmune diseases work. My hope is that [my colostomy] settles things down and gives me a break. I remind myself how full and wonderful my life has been between health crises. I try not to wait to feel perfectly well to do the things that are meaningful to me and just do them in whatever way I can and give myself permission to be accommodated and to ask for what I need, emotionally and practically. And when I feel like shit or super sorry for myself, I take a day in bed and really give into it. Usually, after enough crying and sulking and cocooning, I feel ready to try again.* (R6537)

Similarly, user R6247’s shared their experience of grief since having an ostomy and described grief as a rollercoaster as opposed to neat, linear stages.

> *When we think of the well-known 7 stages of grief they are often set as a row. First Shock, then denial... [etc.] But it is more like a rollercoaster of grief. Shock, denial, acceptance, denial, depression, denial, bargaining, understanding, back to denial, back to shock, etc. This will last a different amount of time for everyone. You've lost something, even if it was just the way you pooped or putting on an old pair of pants and you have to allow yourself to feel those feelings.* (R6247)

This theme, Loss and Grief, has three subthemes that describe various elements of grief: Anger and Injustice, Incongruence with Expectations, and Unacceptance, which refer to feeling angry about life circumstances, facing a reality that is different than what a person anticipated from ostomy surgery, and feeling unable or choosing not to accept their life with an ostomy, respectively.

3.4.3.3.1 Anger and Injustice. Many people posted feeling angry about how having an ostomy changed their way of living and thinking that their life circumstances were unfair. Several Reddit users explained how they had avoided ostomy surgery for years and were angry when they required the surgery. User R6033 (age 20-29) shared his effort to move from his anger to focus on the positive aspects of life with his ileostomy.

> *I told [my doctor] I'd rather die than have the operation. […] within 3 years my colon turned into paper mâché. I had to have the surgery I despised. At first I was depressed and pissed and miserable but life happens and there's no turning back. Despite the downsides, I'm happy I have my quality of life back, I'm not in near constant pain and even though I'm still self-conscious about the bag, […] I'm finding ways to be happy. I'm not going to spend the rest of my (hopefully) long life being pissed about what happened.* (R6033)

Many people explained how having an ostomy ruined normal participation in holidays or life events, or even attending a loved one's funeral. Such experiences were difficult for them and their family members. For example, user R5230 commented on how her fiancé had had trouble managing colitis during major events in his life:

> *I (22F) have been alongside my fiancé (23M) for the past six years, with the last two being consumed by Ulcerative Colitis. He tried countless medications that were not effective. Ultimately, it came down to the fact that he had to have his colon removed. So we spent a week in the hospital over New Year's doing just that… Ulcerative Colitis had taken over his life. I can't tell you how many times he's shit himself or we had to stop on the side of the road to shit. He had to shit in the car at the cemetery during his dad's funeral. And then we spent that night in the hospital getting him a blood transfusion. It will forever haunt me that my loving fiancé had to go through all this. I'm actually in tears right now thinking about it. He is only 23. Nobody should ever have to go through that, especially those of us who are still so young.* (R5230)

3.4.3.3.2 Incongruence with Expectations. People were often upset and frustrated that their ostomy did not give them the life they expected; people hoped that their ostomy would control their symptoms and be relatively easy to manage and live with. Users often based their expectations on others' experiences and were discouraged by differences, for instance, R8423 shared: *"I do not understand how some people have perfect stoma lives, either, but they do, and I do not, and that makes me hate it even more."*

People with new ostomies, particularly those with IBD, were often eager to have their ostomy control their symptoms and offer relief from their disease. However, recovering and adapting after their surgery took longer than some hoped. For instance, user R1278 shared: "*Everyone keeps telling me 'oh it gets better', or 'your stomach slows down', 'you'll stop outputting so much'... but can I ask, when? I'm almost 5 weeks in, and I feel like absolute garbage."* Likewise, users often spoke of how they expected their QOL to improve after ostomy, but that was not always the case. User R8328 lamented their frustration from their new ileostomy not bettering their life that they expected:

> *The more I read stuff on the Internet, the more cheated I feel. Before my surgery, everyone, both on- and off-line. raved on about how much better my life would be post-op. [...] Honestly If I could go back in time and undo my surgery I would. I wasn't this miserable when I was sick [from ulcerative colitis].* (R8328)

3.4.3.3.3 Unacceptance. Some people were unable to come to terms with their ostomy and choosing not to embrace life with an ostomy. Some users preferred their life before having an ostomy, despite persisting symptoms of their illness. User R8423 commented "*I agree that my butt is defective, but I think I hate my stoma more*," and refuted the idea that 'there were no bad stomas' as a blog had stated, saying "*no bad stomas, Oh, well, that is just BS [not true]. There are definitely a handful of us on here that are NOT having a grand ol' time with their stomas*."

Reddit users who did not embrace their ostomy felt that it was taboo to talk negatively about their ostomies since the majority believed their ostomy had improved their lives. User R5313, a middle-aged woman with an ileostomy due to Crohn's disease pointed out that being able to speak negatively about ostomies should be acceptable:

> *We do have a reason and a right to cry, to complain bitterly. We had a very basic thing we've always had removed. Things have changed so much for us. We don't function like others, we won't ever. I've spent a lot of time crying, feeling broken, less than I was. [...] This shit is awful, and it's normal to be angry, hurting and depressed.* (R5313)

Many who were not accepting of their ostomy discussed the possibility of a reversal surgery or the creation of a j-pouch because they wanted a “normal” life and body. User R8328 was contemplating a j-pouch regardless of how it affected their symptoms.

> *It's my vanity that makes me want the j-pouch, but honestly it hasn't been easy to "get over it". I realize that I'm only four months post-op [from ileostomy surgery], and that things might change [...], but I feel like if there's a chance I could get a "normal" body I'd like to give it a try rather than living the rest of my life wondering if it would've worked out. [...] I'm willing to deal with 20+ BMs/day if it means I get to go normally.* (R8328)

3.4.3.4 Change in Ability to Sleep. Having an ostomy had a negative impact on people’s ability to sleep, often because users were worried about experiencing a leak in bed, and/or because their ostomy bag was filled with gas. User R9480, who had an ostomy that was later reversed, commented on the issue:

> *Besides not putting the bag on correctly when I first got it, I'd say my biggest struggle was sleeping. Between only being able to sleep on my back and the bag filling up with gas, sleep was at a premium*. (R9480)

Many also indicated that they changed their eating habits to limit their output at night by restricting eating after a particular time. Strategies of any type seemed to come with drawbacks and mixed success, as illustrated by user R5374 who had a new ileostomy.

> *Anyone else having their dinner at 4-5PM? My goodness - I eat a small dinner at that time and empty out my stoma at 10pm, yet I still wake up in the morning with my stoma bag half-full. Admittedly I don't have to wake up at 2AM, which is the only good thing, here. The whole sleeping and eating process is the worst part of this condition, in my subjective opinion.* (R5374)

Some users had reconciled with the fact that various strategies did not work for them, and learned to live with disrupted sleep, such as user R7878:

> *I think with an ileostomy you are definitely going to have to get up throughout the night. At least that is everything I have read and in my 3 years of having one have never slept through the night […]. Or you could always buy the nighttime bag, if you don't mind having a litre bag on you all night. Haven't done it, for some reason to me it seems dehumanizing.* (R7878)

Several people who have had their ostomy for an extended period also offered comfort to people with a new ostomy by offering reassurance that things would adjust with time, and they would feel more relaxed when managing their ostomy. R5313 (age 40-49) had settled into a nighttime routine that worked for her:

> *I've had Oscar the Pouch for nearly two years (I think). First several months I was having a hard time sleeping, I set alarms to wake me every 3 hours. Eventually I leaked less and woke sooner if a leak started. I sleep through the night (10 - 7ish) getting up maybe 2 times to either burp the [ileostomy] bag or drain it as needed. I do sleep [with] a body pillow and try to sleep on the opposite side from my stoma.* (R5313)

3.4.3.5 Mental and Physical Exhaustion. Ultimately, the combination of disease symptoms, surgeries, medications, and complications took a toll over time and exhausted people both physically and mentally. Many Reddit users highlighted the length of time they have lived with their disease, the number of medical procedures they have received, and the physical and mental drain that they have felt from it. For example, user R5304 highlighted how much of their time since having IBD has involved trialling various medications and stress from contemplating surgical interventions.

> *I've been struggling with [ulcerative colitis] for about 7 years now. I've been through basically all the medicines on the market including remicade, humira, entyvio, stelara, cimzia, xeljanz and others. This past year has been the worst of my life, and I've […] barely been able to stop taking prednisone. So surgery seems like the next logical step. I've thought I was ready for surgery many times, but honestly I am terrified.* (R5304)

Oftentimes, symptoms and complications were episodic and unexpected, rather than experienced gradually over time of living with their disease. The periods of time when a person had an increased need for medical management disrupted an individual's life and caused anguish for people. To illustrate, a partner of a person with an ostomy provided an account of his wife's experience undergoing several surgeries since acquiring her stoma, and the toll it took on their lives:

> *We are exhausted both mentally and physically. The doctors says there is no guarantee that this won't happen again. We are living in life of fear every single moment. We are measuring intake, output, following diet, drinking lot of fluids etc. Still, she is not on her good self. She hardly gets a good night sleep.* (R2859)

Likewise, user R5057 commented on how the constant vigilance contributed to her mental health and how an unexpected issue could cause a setback in her confidence:

> *I've had an ostomy on and off since I was 17 […] it does suck! I'm really depressed!! (to be fair, I've had clinical depression/anxiety since before my surgery, but it's definitely made it worse) sometimes I'll get into the groove of things and bam, leak! or worse, obstruction and I'm in the hospital for days. I hate the constant vigilance – it's mentally exhausting.* (R5047)

In most cases, there appeared to be a cycle of feeling ill and recovering that contributed to feeling fatigue with living with illness. They described how the repetitiveness of the illness cycle took a physical and mental toll on them and their ability to bounce back from being sick. User R5655 described the ongoing patient experience by commenting, "*Serious illness after serious illness, surgery after surgery… they knock you down and you keep getting back up, but each time, you're maybe getting up more slowly, and you're a little more unsteady*." Some were frustrated by the exhaustion they experienced because they felt the situation was out of their control. User R5612 (age 20-29) described his ongoing struggle in trying to have a "normal life" and how his disease held him back from what he wanted over and over again:

> *I've gotten close to being physically fit like I was before my Crohn's started and each time I feel I'm on the cusp, something catastrophic happens and I'm in the hospital for surgeries again, back at square one […] I've tried going back to work 3 times since I got sick. Each time I last a couple of months and then something happens that lands me back in the hospital. It feels like I'm fighting for a normal life and various problems have me by the ankles trying to pull me back. It's so exhausting.* (R5612)

Other Reddit users had developed ways to mentally cope with their situation, though there were still times when their mental health was strained. User R5047 (age 20-29) reflected on her experience and approach to coping mentally, commenting:

> *I'm doing...ok. I'm depressed but feel pretty decent most of the time. For one thing, it just takes time to adjust. A LOT of time, more than you'd think. You do eventually get used to it and it just becomes your reality. You'll hit some snags but you'll be able to handle them better. Also, therapy, lots of it. I find it difficult to talk about even with a therapist, but it definitely helped. I'm on [medication] as well which has helped my overall mood. Having a support system - some of whom I can talk about the bag with, and some of whom don't know at all (because it makes me feel normal).* (R5047)

Another coping technique observed on r/ostomy was the naming of ostomies to separate one's identity from that of their stoma. User R4365 explained this technique by writing:

> *Naming the stoma can be helpful for the patient's mental health. You'll notice a lot of people on here [Reddit] name them. For me it helps separate blame for stoma accidents from me. It's also a covert way of making it clear to my partner that we need to rule out certain options for meals with a group. Russell [my ostomy] shits the bed, not me. And though I love Greek food Russell just can't manage it, so I remind my partner that Russell won't like it and he backs me in steering the group elsewhere.* (R4365)

For some people, being open about having an ostomy helped them. For example, user R4065 described how she believed her openness supported her mental well-being.

> *Honestly I […] tell everyone. Obviously all my friends and family knew I was sick for a decade, and definitely knew when I finally had surgery. [I] started a new job ~4 months later and told my boss on my second day, and basically told everyone at work through normal conversation over the next weeks and months. When I*

> *meet new people it comes up sometimes, and if it doesn't and I get really [worried] then I'll probably bring it up anyways […] [On] my 6-month surgery anniversary I posted a photo with the bag on my Instagram. […] I think because of my positivity and openness when talking about it, I have never gotten a negative reaction from anyone.* (R4065)

There was a consensus among Reddit users that having an ostomy required more than *physical* adaptation; a *mental* adaptation was needed too. User R8767 expressed how they wished that they had sought mental health support before having surgery for their ulcerative colitis:

> *One thing is to take care of your mental health, take advantage of the social workers at the hospital. This is a big physical change, make sure you take care of your emotional and mental health as well. I wished I saw a therapist pre-surgery, but [I] am currently seeing one now and they are helping me.* (R8767)

3.4.3.6 Suicidal Ideation. Some people had experienced an extremely negative effect on their mental health because of their reliance on an ostomy and had trouble coping with their life changes; sometimes these people had thoughts of ending their lives. Changes in mental health were commonly discussed by users who had very recently acquired an ostomy, some of whom were still in the hospital. User R9597 (age 40-49) noted the mental turmoil experienced after his emergency ostomy surgery:

> *I sometimes wish I didn't survive [the] operation- all the possible issues, I'm so scared - I need support to survive. [The]* first *time they emptied the bag I started balling that this is my life now [it's so] raw and life-changing*. (R9597)

Similarly, user R5612 (age 20-29) had recently had a second ostomy created which was permanent, and he was having difficulty coping with how his ileostomy changed his life.

> *I've tried so hard to remain positive about it all but this self-hatred runs so deep. I feel so alone and sad all the time. It's easy to feel everything I used to be has been stripped and now I'm a husk of my ideal self.* (R5612)

User R6719, who has lived with IBD for years, described how their surgeries and complications were the primary focus of their life for 15 years; this prevented them from living life how they would have wanted and caused thoughts of suicide.

> *It wasn't so much the horror of everything as the TIME it took. I was in and out of hospitals for years, trying everything […] and had nine major surgeries with complications each time. By the time I got my life back, there was no life left to return to. Everything changes in 15 years; people age and move apart, college is no longer easy to return to, the world is very different, […] I should be grateful I'm healthy now, I'm mentally sane, not mobility limited, my ostomy works. But my 20s and some of my 30s are gone. I dropped out of college. I don't really want to do anything in life anymore. I had such promise, too. But all I want now is to take pills and sleep. F this disease… The worst thing is I got through the disease, I thought it was over. It's complications, and drug addiction, and mental trauma that's taking me down. […]. I'm not so young anymore. If I don't move past this, it'll will have taken my whole life.* (R6719)

Like user R6719, many users experiencing suicidal thoughts felt like so much of their situation was out of their control, and during moments of ostomy malfunctions, they felt particularly vulnerable. User R1376 (age 40 to 49) experienced a low when he had an ostomy leak because he ran out of ostomy supplies due to a shipping issue:

> *But I ran out of paste and rings and with a deep concave stoma can't really substitute or do without them. I had a blowout, and there I was unable to do anything. I ended up lying down on my side in my cramped bathtub […] And I felt so humiliated and disgusted I just wanted to die. I was thinking if I just had the means to kill myself then I would have.* (R1376)

User R6226 experienced suicidal ideation and believed mental health was a long-term concern for people with ostomies, commenting, *"I [would] be lying if I said thoughts of ending it all haven't crossed my mind. Especially when, for many of us ostomates, this will be a lifelong issue. The mental game is just as hard as the physical."*

3.4.4 Interactions with the Health System

Reddit users often discussed their experience interacting with HCPs and described examples of both positive and negative interactions. Positive experiences involved a person feeling listened to as a valued member in decision-making and feeling supported when adapting to their new reality. User R6770 expanded on this idea of good care and had this advice for a Reddit user who was early in their career as a medical professional:

> *My best advice is to really listen to your patients. I was freaking out about having to have a permanent stoma due to rectal cancer and it wasn't until I met my stoma nurse and she took the time to listen to all of my concerns and talk me through them that I felt that I could deal with it. She was also wonderful at training me to deal with it myself, but she didn't treat me like a stoma with a person attached, but rather as a person who happened to have a stoma, if you know what I mean. We talked about all sorts of things in our early visits - she built relationship. I felt it was crucial to me accepting it all. Encouragement is key, even when we are adults we like to be told we are doing well, and on some of those early days it can make all the difference. Even if it is to affirm to the patient that their stoma is healing well, or is a lovely pink, or their bowel is working fine...we all need that little pat on the back in these delicate situations.* (R6770)

Negative experiences included unhelpful handouts, lack of compassion from providers on the hospital ward, and superficial discussions of life with an ostomy – where practical management was discussed but mental health and psychosocial elements were not.

We identified three commonalities across users' narratives: users often sought and valued advice on certain topics from people with lived experience rather than from HCPs, users stated that HCPs were sometimes too optimistic given the difficulties at hand, and many people felt there was a lack of support for mental health. Hence, this theme has three subthemes: Technical Knowledge vs. Lived Experience, Overly Optimistic, and Lack of Mental Health Resources.

3.4.4.1 Technical Knowledge vs. Lived Experience. On several occasions, Reddit users described how hearing from others with lived experience was sometimes more helpful than the technical knowledge of HCPs. Throughout r/ostomy, users would confirm which suggestions from HCPs were useful, state what advice should be ignored, and offer new advice from personal experiences that are not in common literature. User R4651 explained how r/ostomy was a good resource for people with new ostomies.

> *But they [HCPs] don't live with an ostomy. So, they don't really know what it's like to live with one. Once you've had your surgery, you'll have a lot more questions. I would recommend coming here for those [questions].* (R4651)

Knowledge from lived experience involved unique remedies to managing symptoms, such as eating marshmallows to slow output, drinking soda or tea to help resolve intestinal blockages, and adding hydrogen peroxide to an ostomy bag as an inexpensive deodorizer.

Sometimes, the individuality of experiences caused people to doubt expert knowledge. For instance, user R7916 described how they read literature about what to expect during their adjustment to having an ostomy, but their experience differed.

> *My diet changed quite a bit after my ostomy. I was already low fiber to begin with but I really can't eat many vegetables without complications. It's a pain in the ass. Most of the literature I've read has said you only need to restrict your diet for the first 6-8 weeks and then you can slowly resume a regular diet but that hadn't been the case for me.* (R7916)

Further, there was an element of distrust and skepticism that led many people to question or challenge what they had been told by HCPs. For example, user R1008 shared:

> *I think a lot of the "food to avoid" advice is the medical staff covering their bases. Once you are far enough post-op to not have internal swelling, it should be fine. I've been eating sweetcorn, popcorn and pulses etc. with no issues. Do, however, ease yourself into it with small amounts, and stop if you start to feel extra pressure or other issues.* (R1008)

Similarly, user R4864 discussed how she found some advice from HCPs unhelpful and unpractical after her ileostomy surgery.

> *I think most of us got that list from the hospital after surgery of foods that increase ostomy output odor and things that lessen it. I never paid much attention because I don't really think forcing yourself to consistently eat the limited number of odd*

> *ingredients that lessen odors while avoiding a long list of healthy foods that can cause odors is beneficial or realistic.* (R4864)

3.4.4.2 Overly Optimistic. Some users discussed how some HCPs were overly optimistic about a patient's future with an ostomy and the optimism of HCPs undermined the difficulty of the new reality of having an ostomy. Many people described how they needed support to come to terms with the negative aspects of having an ostomy. User R9597 (age 40-49) described how his nurse focused on the positive aspects of recovery, but he was having a hard time coping with the changes he was facing.

> *I just had my first visit with stoma nurse yesterday and nighttime reality [is] setting in when they go - its all upbeat when [the] nurse/trainer is talking to you - you will be back at work and life in a few weeks ... then at night as you recover and reflect [you realize] life with [an ostomy] is one huge life-changing experience.* (R19597)

Users were particularly frustrated by the optimism of HCPs when they experienced difficulties with their stoma or ostomy appliance. For instance, user R8423 described how their stoma did not work the same as others, and they felt unheard by HCPs: "*They look at the positive and say what works for others. They aren't figuring out what works for me.*"

People also pointed out that pictures or videos with tutorials on stoma care were unrealistic – they either were cartoon images or depicted a 'perfect' stoma on a thin body where skinfold was not a concern. This issue led to providers not discussing the recovery experience effectively. User R1376 highlighted how he wished both people with ostomies and HCPs would acknowledge and discuss the difficulties of living with an ostomy:

> *I [watch] various videos and talk to [nurses] (none of whom [have ever] had [...] a stoma). But it seems like everything is geared towards 'Hey, here's some tricks to make it really work but all in all isn't this GREAT? I'm going hiking and hopscotching and swimming tomorrow!' Nobody who has lived with the real nightmare scenarios seems willing to speak of them in their bald truth, only as past dismissed and underplayed things, or no problems at all. Even the ostomy*

> *nurses who were supposed to prepare me for it before and after the surgery wore some silly sewn felt apron with cartoonish stomas on it to demonstrate pouch application. […] It was all this'll really be great, it'll give you back a normal life, blah blah blah.* (R1376)

3.4.4.3 Lack of Mental Health Support. Reddit users noted the lack of mental health support they received while coping with their ostomy. For example, user R7377 felt uncared for by hospital staff when they were having an emotionally difficult time after surgery: *"It sucks when hospital staff is unhelpful. I ended up breaking down in tears during my last hospital stay [...] because I was having bad leaks while changing and the [staff] were clueless or didn't care."* There was a general sense that routine HCPs that cared for people with ostomies did not play a role in supporting mental health, as user R4458 said: "*The doctor will help you with the physical side of things, mentally it's all up to you."* Further, user R4864 described how she felt that HCPs were not trained or well-equipped to address mental health concerns and urged people to seek formal mental health support:

> *[HCPs] who are not mental health professionals are going to assume you just need to learn about the practical aspects of the ostomy (i.e., that it really shouldn't stop you from living a normal life) and then you will get over any emotions you are feeling. But if that is NOT the case, then you need to speak up and let them know that you need mental health support. Unfortunately, healthcare providers that tend to your physical health are usually not taught to help their patients tend to their mental health (not even to make referrals).* (R4864)

3.4.5 Peer Support

The final overarching theme in this study was peer support. The subreddit r/ostomy was a valued resource and it served as an online peer support group for people who had ostomies, people who were potentially going to have an ostomy, and loved ones of people with ostomies. Some users also spoke about their experience with an in-person support group and the benefits of being able to meet people with ostomies. User R1041 encouraged people to reach out to others on r/ostomy to chat, or to find a local support group to relate with one another and get support.

> *What helped me a lot, before the surgery, was meeting someone who'd had a bag for years and was doing fine. So asking for contacts here is good. If you're in or near a big city there may be an ostomy support group. Visiting a group might help too. There's a big one [group] near me and I went several times. It felt good to know that everyone else in the room was wearing a bag too.* (R1041)

Typically, in-person peer support groups were reviewed as positive, but many pointed out that members were usually older, and therefore dissimilar in age and life stage compared to younger people. For this reason, some people preferred to use r/ostomy to seek peer support.

Users commented that they felt like they could be open with one another and share personal experiences because others could relate and understand. User R5266 underscored the difference in seeking support from fellow people with ostomies versus friends and family: *"None of your friends will fully understand what you've been through and while your loved ones went through the events with you, they had different experiences."* Another person pointed out that the r/ostomy community allows him to feel supported during his recovery with a new ileostomy; the subreddit allowed for open discussion of topics that he felt he was unable to ask elsewhere.

> *I don't know anybody [outside Reddit who has an ostomy] so it's hard to talk to someone about this new lifestyle so I apologize for perhaps asking questions which may seems like common sense but I really don't have anyone else to reach out to other than my surgeon who is super busy doing surgeries now."* (R5462)

This solidarity between people with ostomies was demonstrated by users sharing personal stories about leaks and mishaps, and offering to give advice, message individuals one-on-

one to help them, or send ostomy supplies. Partners and caregivers of people with ostomies shared this sentiment. User R5230, a partner of a person with an ostomy offered support by saying, "*So long story short, there are definitely people out there that can relate to you in some way. I'm always looking for new people to talk to and would love to be a support source for you*." Another user who was about to have their ostomy reversed for j-pouch surgery offered to send expensive ostomy supplies to a person who has recently undergone ostomy surgery:

Reddit users also pointed out the openness of the subreddit, which allowed them to discuss anything related to their ostomy and its impact on their lives. Users valued how open and comfortable they could be on r/ostomy; they discussed subjects that were usually difficult or awkward to discuss outside of the subreddit. As user R5533 said, "*It can be massively underestimated how great it is to have a place to say the gross things and ask questions about sex and life and normal stuff with people who understand.*" Likewise, users indicated that the type of support offered by interacting with others who have an ostomy is unique – different than the care they received from health care providers or friends and family.

Users were grateful for advice on how to practically manage their ostomy during travel, outings, exercising, and continuing their lives. This was illustrated by user R8493, "*This is the part of having an ostomy that nobody else can understand. Traveling. All the small details that come with it and situations like it*." Reddit users were comforted to hear stories from others about how they have coped with living with an ostomy and have not been held back from doing activities that they enjoy in life. To illustrate, user R9597 described his feelings of relief when finding other people with ostomies who continue living life as they want:

> *It's great to know I'm not doomed and can keep living.. .I love this forum. [Seeing people just] living their life has helped me so much [...]. I'm still getting used to the feel of bag when walking and sleeping etc., but this forum and people here have saved my mental health. [Doctors] and nurses mean the best and saved my life but they haven't lived it to help me to thrive after like this forum.* (R9597*)*

3.5 Interpretation of Findings

3.5.1 Introduction

In our study, we analyzed posts from Reddit. These posts included blunt and open discussions of what it is like to live with an ostomy, and users provided very detailed experiences as opposed to high-level or partial recall often provided in traditional interviews. The bluntness and amount of detail provided may be partly due to the ability to remain pseudonymous on Reddit. Based on our results, we expect that social media data may be particularly helpful to explore topics that are uncomfortable for people to openly discuss due to stigmatization and/or people feeling unready to share their experiences (i.e., new diagnosis, poor mental health status). Additionally, many users valued the lived experiences of others and felt that sharing experiences was conducive to good ostomy management and mental health. Users indicated that peer support, (offered by others who have an ostomy) is unique – different than technical knowledge and the care they received from HCPs or friends and family.

However, different social media platforms attract people with varying demographic characteristics, which can cause selection bias. Due to the pseudonymous nature of Reddit, it is difficult to discern if r/ostomy provides a biased sample when considering differences in sex, gender, age, disease status, and length of time with an ostomy. Within this study, users were commonly young people with ileostomies due to

IBD. We expect this observation is due in part to IBD being diagnosed at a young age as opposed to CRC, and the popularity of Reddit among people in their 20s (Lin, 2021). Research published in 2016 highlighted that most Reddit users are men (71%), and 59% of users are between the ages of 18 and 29 (Barthel et al., 2016), but we are not able to discern whether the subreddit r/ostomy differs from this norm.

3.5.2 Cyclical Nature of Adaption to an Ostomy

Reddit users described their experiences throughout their time of having an ostomy and their adjustment to changes. People with a new ostomy often felt overwhelmed by their unfamiliarity with self-management of an ostomy and explained how they felt that their ostomy prevented them from a ‘normal life’ and engaging in activities they enjoyed. Over time, most people became familiar with how to control output and manage symptoms and felt more comfortable in settings outside of their homes. However, people with bowel disease and ostomies frequently experienced setbacks. Rather than a gradual decline in abilities and QOL due to their disease, people with ostomies experienced a decrease in QOL during punctuated events – times when they experienced a flare-up of their disease (i.e., Crohn’s disease) or experienced a complication with their ostomy requiring increased medical management and possibly surgery, such as an intestinal blockage or hernia. The cyclical nature of Recovery and Adaptation, Ostomy Management, and Psychosocial Effects are illustrated in Figure 3.1.

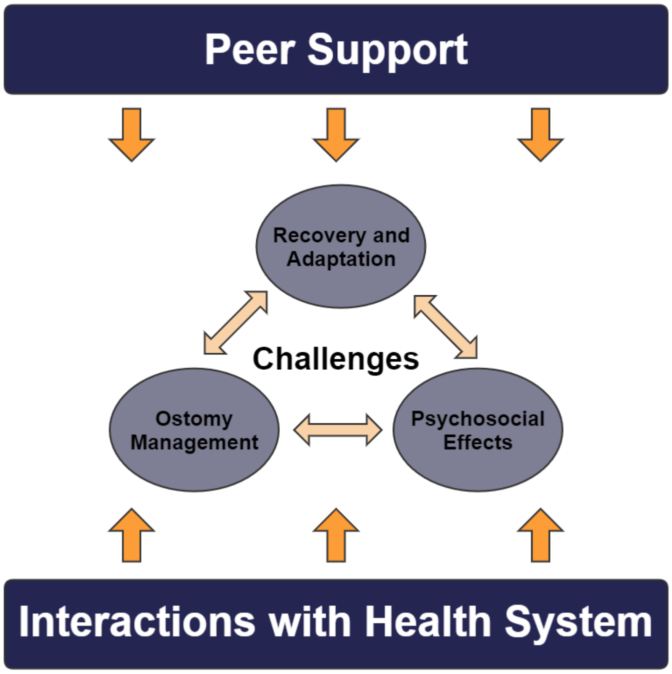


Figure 3.1

Cyclical Nature of Adapting to an Ostomy

Reddit users frequently experienced events (e.g., ostomy leaks, changes in physical appearance, etc.) during their recovery and adaptation. In turn, these changes had psychosocial effects, required new management techniques, and affected adaptation. Also, when a person gained confidence in their ability to manage their ostomy, they improved their ability to cope and adapt to changes and mitigated psychosocial effects. Peer Support and Interactions with the Health System moderated the cyclical relationship by offering support to people with ostomies to cope with changes. Support may be provided in terms of tips to physically manage an ostomy, advice on how to come to terms with having an ostomy and improve mental health, sharing similar experiences, or through answering questions and providing reassurance.

3.5.3 Care Considerations for People with Ostomies

Our findings illustrate several factors that health care organizations and HCPs should consider when caring for people with ostomies.

3.5.3.1 Limited Support for Psychosocial Effects. Reddit users often described how their disease and ostomy caused secondary effects that further impacted their mental health and well-being. Our study results illustrate the severity and urgency of mental health concerns of people with ostomies. Adjusting to life with an ostomy necessitates a mental adaptation. However, many users did not have formal supports to address psychosocial effects; users frequently turned to r/ostomy for advice and help. Psychosocial effects such as changes in body image, anxiety from managing the ostomy, and changes in the ability to sleep affected users' QOL and ability to accept their ostomy. In some cases, people experienced a loss of self-esteem, extreme physical and mental exhaustion, and/or suicidal ideation. Users' experiences speak to the critical need for mental health care to manage the emotional and psychological needs for a person's well-being when living with an ostomy, both during their recovery from ostomy surgery and during their maintenance phase(s). While preliminary research and anecdotal evidence indicates that in-person peer support groups, web-based resources, and telehealth self-management groups can provide support to individuals with ostomies, further research is needed to better understand how to best support mental health and well-being for this population (Byfield, 2020; Cross & Hottenstein, 2010; Pittman, 2017; Weinstein, 2021).

3.5.3.2 The Need for Lived Experience vs Technical Information. The subreddit, r/ostomy offers an online community for those with ostomies and their loved ones. While the rules of the subreddit state that members cannot share medical advice, users routinely share their experiences, support and reassurance, management strategies, and related advice. People frequently stated how much they valued r/ostomy and hearing from people with lived experience, indicating that technical knowledge from HCPs, while important, is not sufficient when learning to live with an ostomy.

Many comments illustrated that people with ostomies view technical knowledge as limited. For example, users sometimes viewed lists of foods to avoid as overly restrictive or unrealistic for an individual. Many believed that information from HCPs may not be the only means for success; they believed in the value of home remedies. For instance, people shared advice to eat marshmallows to slow output before changing their appliance, or to drink carbonated beverages when experiencing a blockage. Users felt that r/ostomy filled a need for information to cope with their condition *realistically*, acknowledging that there is a balance between what is best for ostomy management and eating things that a person enjoys.

3.5.3.3 Individualistic Approach. Throughout the explanation of each theme above, it is clear that not every person experiences the same changes and challenges when living with an ostomy, and there is no single approach to managing an ostomy that suits each individual's needs. Therefore, HCPs must take an individualistic approach to providing care for people with ostomies. This means that many components of physical ostomy management such as finding the best ostomy appliance, adjusting diet, and use of medications/supplements will require trial and error that is (ideally) overseen by the HCP.

Likewise, people with ostomies experience differences in mentally adapting to their ostomy and may have different needs for mental health support. Some Reddit users discussed how their ostomy alleviated their disease symptoms and improved their QOL, which aided them in their adjustment to their ostomy. However, others despised their ostomy and experienced a severe deterioration of their mental health. HCPs should acknowledge that people will experience changes differently, vary in their ability to cope, and have different access to social support. When providing care to a person with an ostomy, an HCP should assess how a person is coping, consider how they can adjust their care and support them, and refer to other HCPs as needed (e.g., psychologists, social workers, etc.).

3.5.4 Implications for Dietitians

Reddit users rarely discussed experiences of dietetic counselling and those that did often commented on how handouts and advice were unhelpful. Our findings suggest that Reddit users would value an individualized approach that takes personal preferences into account. These findings support the need for dietitians to take a person-centred approach during dietetic counselling and consider food preferences and individual aspects of a person's life (e.g., career, cooking skills, etc.). People with ostomies experience differences in symptoms and issues, and as a result, diet is trial-and-error. Dietitians can assist people to find what works well by helping people with ostomies to restrict or introduce particular foods, change mealtimes and food preparation methods, and/or modify fluid intake. Our results also indicate that adapting to an ostomy, like other chronic conditions, is a long-term process that may involve new concerns and symptoms over time. However, unlike other chronic conditions, Reddit users' posts suggest that ostomy care is not structured to provide ongoing care, but rather provide episodic care directed at acute punctuated events or exacerbations. Therefore, dietitians should provide long-term care for people with ostomies and be available as new concerns arise. Lastly, dietitians can help facilitate peer support by organizing in-person or online support groups, providing nutrition and diet information to groups, and dietitians can observe groups and learn from the experiences and needs of people with ostomies.

3.5.5 Strengths and Limitations

This qualitative approach to analyzing Reddit data is novel, and our findings indicate that r/ostomy is a rich data source. Also, we were able to analyze eight years of Reddit data to observe consistent concerns of people with ostomies. However, we were unable to collect complete demographic data for all participants (because not all users disclosed demographic information), making it difficult to compare across subgroups. Given the limited and incomplete demographic information of Reddit users, we could not divide the data to look at specific subgroups (i.e., people with IBD or people with cancer). Further, because the subreddit posts occurred over multiple years, some demographic data may have changed between a user's posts or comments; meaning, a person may have initially posted when they had a new ostomy and was recorded as such, but their more recent quotes may have occurred years later or even after their ostomy was reversed. We were also not able to identify the geographic location where Reddit users lived and sought health care, so we were unable to assess differences in experiences related to the health care setting. Additionally, when selecting keywords to search r/ostomy, we may have missed applicable terms and subsequently, we may not have retrieved all relevant subreddit posts. Lastly, some threads have comments that were deleted by users and that data is missing; however, this did not appear to have a noticeable impact during data analysis.

4.0 Exploring Experiences of People with Ostomies in Newfoundland and Labrador

4.1 Methods

In this study, we conducted semi-structured interviews with people who are living with an ostomy in Newfoundland and Labrador (NL), to better understand their food- and nutrition-related concerns and their experiences of dietetic counselling and health care. This study directly addresses research objectives:

1. To describe the nutrition, food, and lifestyle-related concerns of people living with ostomies immediately after ostomy surgery and during ongoing self-management.
5. To describe patients' experiences of dietetic counselling.

And indirectly addresses research objectives:

2. To describe the model of care in NL for people with ostomies.
3. To describe the role of dietitians and their interactions within an interdisciplinary health care team to provide care to people with ostomies.
4. To describe the current practices of dietitians who counsel people with ostomies.

4.1.1 Recruitment

Participants of this study included people at least 18 years of age with a previous diagnosis of colorectal cancer (CRC), inflammatory bowel disease (IBD), or diverticular disease, who have an intestinal ostomy that was created in NL, and who speak English. Anyone with an intestinal ostomy as the time of interview was eligible, regardless of the length of time that they have had their ostomy. People with a *urostomy*, (ostomy for diversion of urine), were excluded because of the difference in nutritional concerns (Mahan et al., 2012). As described in the COVID-19 impact statement, the ongoing pandemic affected possible recruitment strategies because we were not able to recruit people in-person at hospitals or support groups. We recruited participants over four months (January to April 2021) until saturation was reached. Saturation was reached when no new information or constructs were collected in interviews (Green & Thorogood, 2018).

In an effort to ensure authenticity of our results, we aimed to recruit participants from across the province (Polit & Beck, 2014).We recruited participants by distributing our study information to ostomy support groups in St. John's, Corner Brook, and Gander (run by the Ostomy Canada Society) by emailing the support group leaders and providing them with a digital advertisement to distribute by email and social media, as in-person meetings were on hold throughout 2021 due to the COVID-19 pandemic. We also recruited participants from clinics where patients are seen for follow-up by their surgeon or nurse specialized in wound, ostomy, and continence (NSWOC) after their ostomy surgery. In these clinics, we provided postcard-sized handouts to three NSWOCs in NL who agreed to distribute the handouts to eligible patients. The digital and postcard-sized handouts for each potential participant contained a short description of the study, estimated interview length, and a phone number and e-mail address of the researcher (Appendix C). Participants were offered a $20 gift card as an incentive for completing the interview, which was also noted on the handout. We also used snowball sampling to recruit participants (initial interviewees were asked to recommend other contacts who fit the research criteria). When potential participants contacted us by email or telephone, we screened them for eligibility, sent consent forms and a brief demographic questionnaire, and scheduled an interview.

4.1.2 Data Collection

Our questionnaire collected data on age, sex, gender, diagnosis, and type of ostomy (Appendix D). We used a semi-structured open-ended interview guide (Appendix E). Interview questions were based on the current literature and findings from the Reddit Study.

Participants were offered to participate in interviews using their preference of Webex videoconferencing or telephone. All interviews took place over the phone. Given the gender differences of people with ostomies within the literature and the potential sensitivity of questions on sexuality and body image, Richard Buote (he/him) interviewed men, and I (she/her) interviewed women (Gautam & Poudel, 2016; Karabulut et al., 2014). At the beginning of each interview, the interviewer introduced themselves, reviewed the purpose of the study and the consent form, and reviewed measures to protect confidentiality. The interviewer also answered any participant questions. Once consent was verbally confirmed, the interviewer began asking questions outlined in the interview protocol. These questions asked about any changes that patients experience due to having an ostomy, such as changes in diet, body image, relationships, and daily activities. We asked people how they cope (or coped) with those changes, how they self-manage their ostomy and underlying condition, who had supported them, and we asked them to reflect on their quality of life (QOL) since the onset of their disease symptoms and throughout treatment. We recorded interviews using a voice recorder, and the interviewer took brief notes throughout the interview.

During interviews, the interviewer asked open-ended questions and probed for further information and clarification of responses. We used member checking to ensure the accuracy of our findings by summarizing participants' responses during the interview and allowing the participant to correct or clarify their responses (Candela, 2019; Hadi & Closs, 2016). Once all interview questions were answered, we asked participants for additional comments.

4.1.3 Analysis

Buote and I kept notes to record thoughts and perceptions following each interview and we met to discuss his notes after each interview he completed with participants. My journal highlighted emerging ideas and any observations made during the interviews (Atkinson, 2007; Hadi & Closs, 2016). I or a member of Memorial University's Health Research Unit transcribed the interviews, and I assigned randomized three-digit ID numbers to each participant to ensure confidentiality. During transcription, careful consideration was taken to include pauses and emphasis to ensure we did not lose the character of what was spoken. All quotations are in the English dialect spoken in NL and include many local and idiomatic expressions.

I recorded thoughts and observations throughout the coding process to facilitate reflexivity, including notes of similarities and differences between transcripts, potential themes, and how themes related to one another. As a pragmatist, a key purpose of my journal entries was to better understand experiences of people with ostomies receiving health care in NL and identify practical solutions to address concerns (Long et al., 2018; Giacomini, 2010). I used my notes throughout my analysis and writing to ensure data analysis and presentation were consistent with initial perceptions (Hadi & Closs, 2016). My supervisor and I developed a coding template by independently reviewing and coding the responses of three transcripts and highlighting key themes (Given, 2008; Green &

Thorogood, 2018). We then met to compare and discuss individual codes and we reached a consensus on recurring themes and their descriptions and created the final coding template (Green & Thorogood, 2018). We used Nvivo software to code and group the data. To strive for trustworthiness and allow other researchers to assess transferability, I maintained an audit trail throughout the study which included all interview recordings, transcript versions, and documentation of coding decisions (dependability and confirmability), and we used thick quotes in presenting the data in the analysis to ensure that quotes were interpreted in context (credibility; Green & Thorogood, 2018; Kuper et al., 2008).

4.1.4 Ethics

This study was approved by the NL's Health Research Ethics Board (HREB; Appendix F). Once approval was received from the HREB (Reference 2020.061), we submitted our proposal to the research review committees of each regional health authority in the province: Eastern Health, Central Health, Western Health, and Labrador-Grenfell Health. Each regional health authority approved the study.

To protect the confidentiality of participants, we use random three-digit IDs and do not reveal participant identities in reports and presentations. However, participants may be identified by deductive disclosure due to traits making them identifiable, such as unique patient experiences. To further prevent identification, we edited quotations to remove any names of participants' health care providers (HCPs) or support group leaders and removed names of cities and towns mentioned. We informed participants that they could withdraw from the study at any time. There were no perceived high risks associated with participation in our study. At the end of each interview, we provided each participant with a list of supports and services available to people living with ostomies which included contact information to consult a dietitian, counselling services, and information about ostomy support groups.

All data were password protected and accessed from an encrypted hard drive. Only the researchers involved in this study had access to these data. The study data will be destroyed five years after completion of the study as per the university's regulations. We will make a summary of our findings available to the Ostomy Canada Society so that participants can be informed of the results.

4.2 Results

Thirteen people expressed interest in the study; one person was not eligible for the study based on their type of ostomy (a urostomy), and two people ultimately declined an interview. Between February and April 2021, we interviewed 10 participants. Interviews lasted 28 to 80 minutes.

The majority of participants had lived with an ostomy for 10 or more years, and most lived with an ileostomy (Table 4.1). Participants were between the ages of 40 and 79 and all 10 participants were cis-gender. Preferred pronouns were used throughout the interviews and in writing. Six participants lived with a form of IBD, three participants had a diagnosis of CRC, and one participant had diverticular disease.

Table 4.1

Summary of Demographic Characteristics of Participants (n=10)

Characteristics	n	Characteristics	n
Age		**Diagnosis Resulting in Ostomy**	
40-49	2	Cancer	3
50-59	2	Crohn's Disease	2
60-69	3	Ulcerative Colitis	4
70-79	3	Diverticulitis	1
Sex		**Type of Ostomy**	
Female	7	Ileostomy	7
Male	3	Colostomy	3
Gender[1]		**Length of time having an ostomy**	
Women	7	5-9 years	3
Men	3	10-14 years	4
Community[2]		≥ 15 years	3
Urban	7		
Rural	3		

1 – Gender was self-reported using an open-ended question, only two gender types were identified by participants.

2 – Communities were classified as rural if they were not included in a Census Metropolitan Area, Census Agglomerations, and/or had a population of fewer than 5000 people (Government of NL, 2019).

We identified four major themes (Adjusting to Change, Physical Health Challenges, Psychosocial Impact, and Sources of Support) and 16 subthemes (Table 4.2).

Table 4.2

Organization of Themes and Subthemes Within Patient Study

Major Theme	Subtheme
Adjusting to Change	Experience of Living with Illness Prior to Surgery
	Disruption of Normal
	Developing Self-Management and Coping Skills
	Adjustment to New Normal
Physical Health Challenges	Common Ostomy Issues
	Hernias
Psychosocial Impact	Stigma
	Body Image
	Sex and Intimacy
	Vigilance and Fatigue
Sources of Support	Partner or Spouse
	Family and Friends
	Health Care Providers
	Peer Support
	Ostomy Supply Companies
	Workplace

4.2.1 Adjusting to Change

Across all interviews, participants highlighted the iterative process of adjusting to changes in one's life that have been caused by illness and/or treatment of disease (Figure 4.1). People had diverse experiences in terms of symptoms of their disease before having an ostomy and their 'normal' way of living. Acquiring an ostomy disrupted a person's perceived normal, but over time people learned how to cope and how to self-manage their condition, which led to their "new normal." However, people's experiences differed; they spent varying amounts of time in each phase and moved back and forth between phases of adaptation as new changes and setbacks occurred. For example, if a person who was well-adjusted to their ostomy encountered a setback (such as complications with their stoma or ostomy appliance), they experienced disruption and had to learn new self-management skills. Therefore, this theme has four subthemes that refer to each phase of the pathway of adjusting to change: Experience of Living with Illness Prior to Surgery, Disruption, Developing Self-management and Coping Skills, and Adjustment to New Normal.

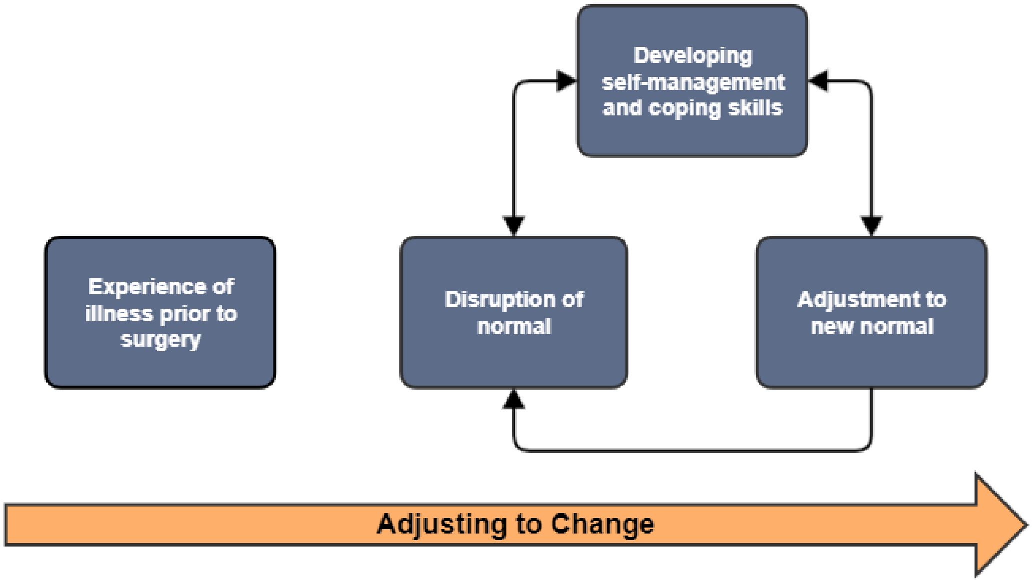


Figure 4.1

Pathway of Adjusting to Change

4.2.1.1 **Experience of Living with Illness Prior to Surgery.** A person's experience of illness before surgery determined the perceived disruption caused by the ostomy, meaning that if a person had persisting bowel-related symptoms such as frequent diarrhea before surgery, the ostomy was seen as less disruptive than if they had no symptoms.

People's experiences varied greatly depending on their diagnosis. Those diagnosed with a form of CRC, experienced few, if any, disease symptoms. In contrast, people who had IBD were often living with a variety of symptoms that ebbed and flowed before their diagnosis and over the course of years of treatment. Their symptoms before having an ostomy commonly included frequent bowel movements, pain, weight loss, and bloody diarrhea. In their day-to-day, they required frequent access to a washroom which caused anxiety and at times prevented people from leaving their homes unless it was necessary. Sometimes, people with IBD also experienced a change in symptoms related to their diet. For some, this resulted in trepidation and feeling unsure of which foods were safe to eat, sometimes causing them to eat a limited or "bland" diet. For example, P357, who mainly experienced pain symptoms of IBD, described his experience before having his ostomy:

> *When my Crohn's was flared up at the worst times you know before the ostomy I was going 20 to 30 times a day. [...] Well see the thing was as I got my diagnosis [...] I started to lose weight, and over that short time span of a couple of months I lost 25 pounds [...], when you're that sick [...] you don't want to eat because you know what you're eating is, it's gonna hurt you.* (P357)

Some participants voiced that they experienced symptoms regardless of what they ate, while others were able to manage their symptoms through diet. P677 had identified particular foods that she could tolerate during a flare-up of her Crohn's Disease:

> *When you're in a flare-up you tend to just eat things that don't bother you at that particular time and for me in different flare-ups different foods bothered me. So I mean I had a very small list of safe foods that I would eat during a [flare-up] and that would be you know toast, white bread toast, boiled eggs, cream of wheat, just very bland.* (P677)

People with IBD received an ostomy to control their symptoms and/or because diseased bowel needed to be removed. Some people opted to have an ostomy to manage their disease while others required emergency surgery due to complications caused by their disease. P519 described how life looked for her before her surgery and why she chose to have an ostomy:

> *I was having a lot of bowel problems. So that was going on for like five years and I was on Prednisone and all kind of different medications and stuff. It didn't, the medication after a while just wasn't doing anything. […] So then I opted for surgery. I decided that I would have surgery. […] [Colitis caused] a lot of diarrhea, really bad stomach cramps, bleeding, […] you can't hold your bowel at all. It just all of a sudden you got to go. It's not a nice condition. […] Anything I ate would give me a really bad stomach [and] diarrhea, it didn't matter what it was*. (P519)

Prior to having an ostomy, P480 who had diverticular disease experienced episodes of severe abdominal pain. He described the pain as constant, which led to him having a colonoscopy and the removal of some of his bowel: "*I was having a lot of trouble making bowel movements and there was always pain. There was chronic pain down in my stomach all the time, so I finally got the doctors to go up and look through."*

4.2.1.2 Disruption of Normal. Participants described how the changes and challenges they experienced after having an ostomy affected their day-to-day activities. These changes occur after first acquiring an ostomy but can also re-occur if an individual experiences a change in symptoms, complications, or receives an additional diagnosis.

For some individuals, their ostomy surgery was elective and planned in advance. For others, the surgery was performed on an emergent basis. Regardless, people still felt an element of shock the first time that they saw their stoma, their ostomy appliance, and how they functioned:

> *When I went for my surgery I didn't know what an ostomy looked like, I did not know until the morning of my surgery when [my nurse] came in for to do the markings where I had to have the ostomy put in through my belly and I didn't even know what I was going to look like and you know when she showed me the pouch […]and I thought you know oh my god I didn't know it was gonna look like this.* (P267)

The first time that a person handled an appliance change after arriving home from the hospital was regarded as a big milestone. The first bag change was an arduous and uncomfortable process that took a great deal of time and patience. Participants said that when they first arrived home, they still felt tired and weak from having ostomy surgery and they needed time to recover and heal, so they usually remained home and restricted their activity. P166 described her experience when first arriving home:

> *Well first when I came home one of my daughter's would [change my appliance], well I was too sick I couldn't sit up to change it, right? But once I got my strength back well the first day, I said to them now I'm getting a bath and I'm going to change my ostomy and I'm doing it myself. So they watched me anyway and I got a bath, and I changed my ostomy but by the time I got it done I was ready to get back in the bathtub because I was sweating.* (P166)

Participants discussed elements of their new ostomy that were unfamiliar at first, and how the ostomy made them uncomfortable. The appliance itself was sometimes viewed as bulky, rigid, and uncomfortable; their ostomy bag would fill with gas and balloon; the appliance may leak or fall off, and some participants feared having a blockage and were cautious about eating.

> *The first [ostomy bag] I had, it must have been about eight inches long and had a clip on the end of it and you put on your underwear then it would be down to the top of my side. [...] at first when I was getting a lot of flatulence the bloody thing would blow up and I was like what the hell? And you'd have to make your way to the bathroom and check and make sure it wasn't stool and it was just gas and [try] to get the gas out of it.* (P498)

Leaks appeared to be the biggest concern that participants had when they first had their ostomy. Leaks were common in the early days after surgery because the stoma could change or because participants were not skilled in attaching their appliance or choosing the best ostomy products for their needs.

> *...but I used to have [leaks] more often in the beginning. When I was pregnant my stoma would change a lot, so it was hard to get a good fit. I was constantly having to readjust so [leaks] would happen more often then but [the leaks were] not always a catastrophic failure. Sometimes it was more like maybe having you know a small leak that I could get home in time to deal with.* (P844)

The possibility of leaks while outside the home was particularly concerning and it took courage at first to feel comfortable going out in public:

> *Well my main concern was leakages at the time 'cause I was like I said you know I'm very strict in what I eat so [I follow] what is being told [to me] by the dietitian and my [NWSOC] in terms of what to eat to avoid blockages right? You know, what not to eat and stuff like that. But the leakages were the main issue at first right? And the fear of you know, especially when you're in public the fear of it just… you know [breaking].* (P357)

In terms of diet, people typically chose to eat very carefully and slowly early in their recovery. They ate soft, bland foods that they felt confident they would be able to digest well and they avoided foods that they were told by HCPs to avoid or foods they felt may be problematic. It was common to worry about the effect their diet would have on their ostomy output and whether foods would cause blockages, leaks, gas, or odour.

> *I had to be very careful; there were some foods that I couldn't have, and I found with this ostomy, the ileostomy, you had to be careful with what you're eating, you had to eat very slowly, you have to make sure your food is chewed well, so that was a change there.* (P267)

No matter how long an individual had lived with an ostomy, it was common to experience some form of complication or change that resulted in new challenges. For example, when P357 developed psoriasis, it affected his ability to work because his appliance would not stay attached:

> *Three to four years ago I developed psoriasis and it's around the stoma and because of that I'm not able to work. I had to fight for disability Canada pension […] And they only approved that because I had a letter sent in from my dermatologist explaining about the psoriasis and how difficult it is to keep a pouch on with psoriasis.* (P357)

Participants cited challenges related to skin integrity, hernias, abscesses, changes in intestinal health, and new diagnoses such as diabetes or celiac disease.

> *[My physician] did a number of tests on me and coloscopies and stuff like this,*

> *checking out to see if there was something else wrong and it was only after I had you know a [colonoscopy] and some bloodwork that it was positively identified as celiac disease, but up to that point up to that point as I say I was running to the washroom about 16-18 times a day [to empty the ostomy bag].* (P802)

4.2.1.3 Developing Self-Management and Coping Skills.

People with ostomies described how they learned to prepare for day-to-day activities, manage their ostomy, and overcome challenges. Over time, participants became much more familiar with their stoma and ostomy appliance, developed strategies to get a good seal of their appliance to prevent leaks, and identified which products worked well for them.

> *Yeah, so it was really hard. I didn't leave my house very much for the first five or six months because I was just really, really, really scared of having a leak. So I pretty much just stayed home and tried to manage it and it was tough I'm not going to lie it was really, really tough those first few months. I spent a lot of time searching for ways that I could improve it you know buying different underwear with pouches inside to hold it up, buying different belts to try and keep it secure, trying every different type of appliance that I could possibly get my hands on at that time, different adhesives or tapes or anything that I could think of. […] I finally found something that worked for me and that was that was pretty much my life for the first five months or so.* (P677)

Participants got accustomed to their ostomy and developed a routine of when and how they would change their appliance; over time, they needed less time to change their appliance and they learned how to get a good seal and fit.

> *You got to keep your skin clean and dry. Make sure your skin is completely dry. Sometimes I'll get a bath and I'll come out I'll put a pad over my ostomy, and I'll put on my housecoat and I might sit down – because I usually try to change my wafer when [the ostomy is] not active, like first thing in the morning or last thing in the night and I'll sit down and for a half-hour or walk around doing something [until] I find my skin is completely dry right.* (P166)

With time, people were less worried about the possibility of experiencing a leak because they felt prepared to handle it and because leaks happened less often once they had improved their skills in securing the appliance. If a leak did happen, people were less upset by them than they used to be.

> *They [leaks] don't happen as frequently. Like I haven't had to leave work in ages. […] I had a really bad one at a work party where it again fell right off my body onto the floor in front of my boss and everyone, that was embarrassing but I think like after everything I've been through in the last few years it just doesn't seem like that much of a big deal, I guess you have a different perspective - it's like oh well that's life.* (P844)

Participants agreed that planning and preparation were key to managing their ostomy while participating in day-to-day activities. People discussed strategies they developed over time, such as keeping ostomy supplies with them wherever they went and having them in the car with a change of clothes in case of leaks.

> *I didn't stop my activity. I did what I could do with my ostomy and I go to restaurants but now like the washroom, you find as you move along you find which areas fits your needs better you know. And even travelling, I've watched and I pick a gas station or somewhere that's got washrooms that's got handicapped washrooms there for people like me. […] But I learned as I went along that ok now you take your emergency kit with you in case you leak and a change in clothes, now that's everyday routine it is.* (P267)

Some people used an ostomy belt or hernia belt regularly as a way to keep the appliance in place and to provide abdominal support, while others found the belts too cumbersome for everyday use.

> *The biggest thing with the ostomy that helped me through the years is the belt that I have that I use for the ostomy because it gives you the confidence to go out. […] the belt gave me a lot of confidence because even when I had an issue that I had to change the pouch, it gave me time to get, to get home. 'Cause obviously you need privacy [to change the pouch] so it allowed me time to get to a private place [where] I could change my appliance.* (P357)

Some participants stated that there was a short list of foods that they learned to restrict to prevent blockages such as lettuce, raw vegetables, fruits with the peel on them, popcorn, nuts, etc. One participant ate smaller more frequent meals to control her output because it was easier for her to cope with managing her appliance. There was a consensus among participants that diet was largely trial and error. For some, this was because of the nature of their disease (i.e., Crohn's Disease), while for others it was because there was a lot of variation in experiences with an ostomy and well-tolerated foods. One participant explained how she modified her diet if she was planning to go out to a theatre show:

> *…we like to go to a lot of shows and performances, concerts, theatre […] and we've always done a lot of that and so you know if something starts at 6:00 p.m. or 7:00 p.m. I really have to adjust my eating and drinking so that I can sit through an hour-long performance or a two-hour-long performance without needing to get up when it's not appropriate to get up part way through.* (P677)

4.2.1.4 Adjustment to New Normal. Each participant reflected on how they view their current state and the degree to which ostomy impacted their life, and overall QOL. Participants of this study had an ostomy for five or more years, and overall, most were well-adjusted to life with an ostomy. At this stage of adjustment, people viewed their diet as 'normal' even if they had made modifications and restricted foods since having their ostomy. Those who ate with their family still ate the same meals as other family members, the person cooking just ensured the meal was appropriate for everyone. For example. P519 explained: "*my husband, he knows what I can and can't eat and so like we'll have the same. He'll prepare something that he knows I can eat, and he will eat it too right*." Some people were more restrictive than others. There were very few foods that P844 avoided in her diet for example:

> *Now I eat everything like I remember being in the hospital and she [the nurse] told me I would have to cut up grapes if I wanted, actually to peel grapes if I wanted eat them. I don't do that. That I wouldn't be able to eat broccoli. I eat broccoli. The only thing I have really a hard time with is stuff like waxed beans and asparagus I can eat but not a lot of and it's easier for me to digest if it's cooked but like I'll eat [whatever], like today I ate like half a bag of you know that kale, that sweet kale salad from Costco.* (P844)

Most viewed their current QOL as good, and either just as good or better than their QOL before having an ostomy. As P498 put it, "*My quality of life now is the same as it was before, it's just that now I plan things differently.*" Many people expressed their acceptance of life with an ostomy because they were happy to be alive and they felt they had learned to self-manage their ostomy.

> *I remember back when I was getting my surgery, a few weeks before we had lost one of our co-workers and she kind of had the same symptoms as me - she was having bleeding and she ended up being diagnosed with cancer and she passed away unfortunately, and she was only young. And I remember when I came home from the hospital [...] I was really down like I spent a lot of time crying and I was really not accepting it very well. Then one day I just got up and I looked in mirror [...] I said if [my co-worker] was given the chance to have an ostomy and still be here, she would have jumped for it you know. So, I said you just got to get over this and accept it and move on.* (P781)

For those who experienced a lot of gastrointestinal symptoms such as diarrhea before ostomy surgery (i.e., those with IBD), their ostomy relieved those symptoms. While ready access to a washroom was still important, the urgency and frequency of finding a washroom decreased. These participants frequently viewed their ostomy as an intervention that improved their QOL.

> *I was just so sick for five years that I said if this is what's going to make me feel better, I'm going for it. [...] if anything, it's made my life better. [...] I certainly got more confidence, more self-confidence because before I was frightened to death like I always had to make sure I knew where a washroom was to and stuff like that. Now I'm more outgoing, I love to laugh and carry on yeah just it's changed my life a million times better.* (P519)

One person felt that they did not have a good QOL, due to their ostomy. She expressed her frustration because she was told by HCPs that the ostomy would change her life for the better, but that has not been the case. She has struggled with fluid and electrolyte balance, high output, and complications such as an abscess. Ultimately, she felt that her ostomy still limits her ability to participate in day-to-day activities such as shopping, attending theatre performances, and working in an office setting.

> *It's still not great. I don't have a great quality of life. […] I would do a bit of volunteering here and there [before the pandemic] just to get me sort of connected with people and out of the house and the odd time I can go to church, sometimes I can't, sometimes I can [go to] family gatherings that type of thing.[…] healthcare professionals, a lot of them seem to think oh well we're going to give you an ostomy, it will be an adjustment period. You may not want to have a bag on your side but trust me you're going to be glad when you've got it done. And like it seems like most people, most nurses, doctors you know think okay well your life is going to get better now. You're not going to be sick all the time. You're not going to need a bathroom all time and you're going to be just fine. And I was told that quite a lot, but I was never, I never ever got there. I was never just fine.* (P677)

4.2.2 Physical Health Challenges

Participants experienced an array of physical health challenges while self-managing their ostomy. These challenges were either directly related to their ostomy surgery or stoma itself, or an element of their health condition(s). The two subthemes of Physical Health Challenges include Common Ostomy Issues, and Hernias.

4.2.2.1 Common Ostomy Issues. Common ostomy-related issues experienced by participants included high output, leaks, skin irritation, gas and/or odour, skin irritation, dehydration, and blockages. Some issues had a minor effect on their day-to-day lives and ostomy management (i.e., leakage on rare occasions), while other issues were chronic and difficult to overcome (i.e., skin irritation, high output). Chronic challenges were more difficult because they caused their ostomy products to not last as long and required an increase in the duration and frequency of ostomy care. P498 described a time when she experienced diarrhea and high output and the effect it had on her:

> *But every time I turned around I was going to the bathroom and changing my liners. […] and then my flange would probably last me eight or nine days and I would have to be changing every two or three because it was – all the stool was breaking down the wax inside it and then trying to get that thing off your skin […] I was all sore.* (P498)

Maintaining hydration was a difficult balance for some and could cause high output. P844 did not have many concerns about her ostomy but she underscored the importance of staying hydrated with her ileostomy: "*I do have to watch hydration. I find that's the biggest thing that I have to watch and sometimes I get dehydrated.*"

Some people had never experienced an intestinal blockage but had close calls. Those who experienced blockages or near-misses had several contributing factors including the type and quantity of food they consumed, the location of their stoma, and/or bowel adhesions (formed when scar-like tissue builds between loops of the bowels and cause irregular attachments).

> *I could introduce [restricted foods] but I found that [because] I have an ileostomy and [my output is] liquid because I only have a very small opening. If I eat something that I can't digest then like I thicken to the point where it's very hard to get it through my ostomy and it can block me, or sometimes I had trouble because [if] I eat the wrong food [...] it would pop my wafer off.* (P166)

Close calls often involved pain when the stoma was active, and/or thick output could "pancake" – occurring when the thick output stayed at the top of the ostomy bag and created a vacuum between the layers of the bag and could block output. Some participants had required surgeries to address the blockage.

> *Well like I said, I don't digest anything. So peanuts if I don't chew them up really good, they'll come out the same way I ate them so I could end up with a blockage. Peanuts cause what they call pancaking [...] it could cause the flange to come off, leakage. [...] I ended up in the hospital three times with a blockage.* (P519)

One participant had developed an abscess which complicated her care and required a drain to be put in place. This was believed to be a temporary measure but has been needed long-term as the problem has not yet been resolved.

> *I was hospitalized just over a year ago a few times until they figured out what it was and then they had to put this drain in and it was I mean the abscess was I*

> *don't know 10 centimetres long or so it was quite big and they drained off a lot of pus and stuff and I had a lot of medication and antibiotics and [ever since we're] monitoring the drain and I thought it might come out after a few weeks, that's what I was told, but here we are more, way more than a year later with the drain still in place.* (P677)

When a person undergoes surgery to have their ostomy created, their disconnected bowel, rectum, and anus may be left intact with the intention for it to be reconnected later, or, in an effort to minimize the recovery needed after major surgery, to be removed during a second surgery. Often, people with the rectum and anus still intact (commonly called a rectal stump), experience a mucous discharge from time to time, and may feel the urge to sit on the toilet to excrete the mucous. This can be a bothersome side-effect. For some participants, the issue was resolved over time, but one individual had a unique and more problematic experience.

> *Yeah, I guess, well they took out most they call it a subtotal colectomy, but they left, they left in a little bit more than they normally would I guess because I was pregnant they didn't want to go too far up like too far around the uterus I guess. And so I still have like a rectum and stuff and I do pass quite a bit of blood from it from time to time so sometimes that's been an issue and they've talked about having surgery for that but I've managed to avoid it [...] I've had to go on Prednisone and things to sort of deal with that.* (P844)

4.2.2.2 Hernias. Most participants had one or more hernias at the time of the interviews, and their hernias impacted several aspects of their life. At a minimum, participants had discomfort from their hernia, and it affected their ability to bend over and lift things; many people restricted lifting anything in fear of worsening a hernia or creating a new one.

> *I didn't play golf. I was afraid because I do have a peristomal hernia or something and it's been there probably for eight years and that thing ain't going to get any bigger because I'm not lifting anything over 10 pounds and I'm not pushing or shoving or anything.* (P498)

At worst, hernias caused complications for their bowel functioning by constricting the intestines and/or causing blockages and required surgical management to repair the hernia.

> *Less than a year [after getting my ostomy] I had to go back and have another surgery because I developed hernias, I had four hernias. I had to go back and have another major surgery so that affected my life too because in less than a year I had two major surgeries where I had to battle myself back from that.* (P267)

Many participants had more than one hernia over time. Depending on how severe the situation was, the surgeon and the person with an ostomy may have decided not to operate on the hernia unless it became more of a problem, because of the risks associated with surgery and potentially losing more of their already compromised bowel.

> *I got another hernia, so you pretty much got to live with the hernias unless they're causing problems. Like I did go back to my doctor and see about this one and she said they're not going to do anything about it unless they're causing blockages and that's why I had my first surgery [because the hernia] was causing so much blockage right? But as for this one, I haven't had any problems with it, so I just learn to live with it.* (P519)

Having a parastomal hernia sometimes affected how the ostomy appliance fit the stoma and required participants to troubleshoot potential solutions. For some, the hernia also affected their appearance by making a part of the abdomen appear larger than other areas. As seen in the next two quotes, some participants chose to wear a hernia belt regularly for support, while others felt hernia belts were uncomfortable and impractical.

> *I've been wearing an ostomy belt […] That's a big wide belt about six or seven inches wide and it got a special designed hole and a flap in the center of it to put over the flange and that and to keep your stomach in. […] and it's around your back and your stomach and keeping your stomach in place and if you don't wear it well you can actually feel the tendons inside of your stomach tearing all the time which is quite painful. […] [The ostomy belt] keeps it drawn in and keeps it together and you got no strain on [stoma].* (P480)

> *I have a major, a very large what's called parastomal hernia which is a hernia*

> *which is right underneath my stoma [...]. So there's a big bulge out on my abdomen, and consequently it's very difficult for the ostomy appliance and so on to fit onto that and I've been to a number of surgeons [...]. There are hernia belts and so on that you can get and they're the most uncomfortable thing known to man. I've worn them at times but as I say it's not something that you could do on a regular daily basis.* (P802)

4.2.3 Psychosocial Impact

The psychosocial impact of having an ostomy refers to the mental, emotional, and social effects and relates to four subthemes: Stigma, Body Image, Intimacy, and Vigilance and Fatigue. Psychosocial impact varied by participants' unique experiences and personal characteristics such as age and stage of life (i.e., whether or not they were retired), and how well their ostomy was managed.

4.2.3.1 Stigma. Stigma refers to how a person with an ostomy perceives the acceptability of disclosing their ostomy to others and talking about their experience living with an ostomy. At the time of the interviews, most participants felt comfortable disclosing their ostomy to anyone and were open to talking about it with others. P267 was open about her ostomy and hoped it would encourage people with ostomies to talk about their ostomy and learn to accept it.

> *I don't hide that I have an ostomy, I am very open and honest [...] I would tell anybody, if you have to have an ostomy one thing you have to do - you have to accept if you've got an ostomy. Some people like can't deal with it. They're afraid to go outside but you have to learn, especially if you've got a permanent one [...] you have to work with it. [...] you have to learn to accept it and deal with it, not hide, but go and do your everyday activities.*

However, some participants acknowledged that they knew many people with ostomies who did not feel the same way and who did not want to discuss their ostomy because the topic was uncomfortable and made them feel ashamed; they said because people do not talk about bowel movements.

> *It’s like nobody knows about [life with an ostomy] and it’s very hard to get people to open up about it too because I know there’s a lot in our [support] group who didn’t want to get involved in anything […] and all the people are embarrassed about it.* (P498).

> *There’s more people […] that got an ostomy or a colostomy than you’ll ever know but in our support group we’ve only got 10 people right […]. A lot of people are ashamed of it like oh my God I got this on my side, I can’t tell anybody about that. But you know […] it’s no different than if you had breast cancer […]. It’s something that’s keeping you alive but it’s the fact that it’s poop right. Nobody wants to talk about poop.* (P519)

Participant P781 was less comfortable than others disclosing her ostomy and restricted that knowledge to her family and select close friends, saying, “*It’s not something I tell everybody. But you know, all my family knows of course and a few of my close friends know, but I don’t tell a lot of people*.”

Generally, participants felt that they were not treated differently by others because of their ostomy. However, P537 discussed how he felt that his coworkers treated him differently at work.

> *People do treat you differently with it, […] I know there's people that avoided me just because of it. Like I've had a situation where like I've went to lunch at the cafeteria and coworkers […] went to a different table, you know, they wouldn't say anything but it was just their actions give it away right?* (P537)

P480 also pointed out that not only are people sometimes reluctant to talk about their ostomy, but people generally avoid talking about mental health, which can be affected by illness and living with an ostomy daily.

> *My biggest concern it’s not the physical part about it [the ostomy] it’s the mental part of it. […] My opinion is, […] Newfoundlanders don’t talk about mental issues. […] I think people are still not talking about the issues of their life because I never hears anybody talk about it but I knows it’s affecting them because it affects me.* (P480)

There was a consensus among participants that while they felt that talking about their ostomy and how it affected them physically and mentally was an important coping mechanism, not all people with ostomies were willing to talk about ostomies as they are about other diseases.

4.2.3.2 Body Image. Participants generally felt that they had come to a point in their lives where they had accepted their ostomy and how it changed their appearance – although they still did not like how it looked and it still affected their confidence at times. For many, their acceptance was bolstered by having a long-term life partner who supported and encouraged them.

> *I'm still very careful about what I wear and […] I'll make sure I got something covering it, it still bothers me. My husband doesn't care about it at all, but it still bothers me, but I learned to live with it, I get past it and just move on.* (P498)

Some participants also saw their scars as "battle scars" and focused on the fact that they were alive, and that their ostomy helped them along the way in life.

> *I love my ostomy, I do, because it saved my life. It did and I'm [50-60] years old I'm not going to be worrying about body image right you know right. I'm not going to be looking for another man by no means right so no I'm not worried, I got no worries.* (P519)

For many, having an ostomy affected how their clothes fit and how they felt about their appearance in certain types of clothing. Some chose to wear looser clothing – both to protect their ostomy from being pinched and to prevent their ostomy from being noticeable.

> *So I used to like pants a lot more, I used to like pants and shirts but now I mostly wear dresses when I leave my house, and I wear men's gym pants, men's pyjamas when I'm inside my house because the waistband sits a bit higher and they're a bit looser in the leg so that works well for me. And when I go outside my house, I wear a lot of dresses [because] they don't press on the ostomy and I don't have a waistline to cut off the ostomy. Like jeans don't work for me at all anymore because they dig in, they don't sit right, they drag on the ostomy.* (P844)

Many commented on how they worried that their ostomy bag would fill with gas and balloon, causing it to be more noticeable to others. Hernia complications also affected their appearance, as participant P519 described:

> *I ended up in emergency one day because I noticed I had swelling on one side and actually my husband said he noticed it and his brother noticed it, but nobody said anything because they said you don't dare tell a woman she's putting weight on right. So I did notice [the swelling from a hernia] I said my God it seems like I got an awful lot of swelling on one side.* (P519)

Some participants' body image was more negatively affected at the time of the interviews than others. In response to the question "Has having an ostomy changed how you view your body?", participant P677 described:

> *Oh my God yes, so, so much. It's awful. It does a number on you kind of mentally. I also have a hernia [...] I look pregnant all the time. I've had people ask me when I was due which is really disheartening to hear. So between that and worrying about the smell because it smells [...]. So between that and then having to modify every single piece of clothing because I was told back then oh yeah, you'll be able to wear all your clothes. [...] I've had to change everything about how I dress, everything to cover up the ostomy and the hernia not to mention the noise and the smell [...] it does a number on you really, especially [because] I liked how I looked before and then I went from that to just really hating how I look. So it's tough yeah.* (P677)

A change in body image was experienced by both women and men. In response to the same question about whether an ostomy changed how they think about their body, P480 described how having an ostomy affected his comfort level of being able to be shirtless on a beach:

> *It changes everything because if you went to the beach which I don't go to the beaches, swimming pools you're very, very, self-conscious of everything there because you're only wearing a pair of shorts and you really are self-conscious of that.* (P480)

4.2.3.3 Sex and Intimacy. Participants' experiences of how sex and intimacy were affected by their ostomy related closely to how their body image was affected. Most participants had a long-term partner when they got an ostomy and were still with the same partner when they were interviewed. Participants had worried about how their partner would perceive their ostomy and consequently, how it would impact their sex lives. P519 described how one of her key worries before her elective surgery was whether her husband would be accepting of her ostomy and how it would affect their marriage:

> *I was having panic attacks, I was having night sweats […] I tell you the main thing that really scared me was that I figured that my husband was never going to want me anymore. That's what I thought right, and we've been together almost 40 years now […] and I got no complaints there whatsoever, none.* (P519)

Some participants had discovered ways to feel more comfortable during sex. For example, P498 had found a smaller, more discreet ostomy appliance that they used: "*When it came to intimacy with my husband that was a big problem for me and this is where I got this little pouch because I felt [more comfortable with it]."* Similarly, another participant found a method that worked to prevent the appliance from moving and being noticeable during sex; he used Spanx-like material to keep his ostomy close to his body.

Regardless of any coping strategies, most participants stated that their partner said that the ostomy was not a concern during sex, and it did not negatively affect their relationship once the participant got past the mental barrier.

> *It [intimacy] was [a hurdle] in the beginning yeah, it's like you know you don't really want him to look at [the ostomy], even though he had no problems with it whatsoever, but […] I felt that it was terrible you know.* (P781)

However, there was one exception. Participant P480 described how his wife was not comfortable with his ostomy and how feeling it at all made her uneasy during sex and she worried she would hurt him.

> *It really affects my wife. I'm being personal now and I'm going to be honest my wife can't stand to touch it. If she happened to roll over and touch it, she gets*

> *right tensed up on my side then, […] She's frightened to death she's going to hurt me; she haven't hurt [but she is] self-conscious of touching it […] she can't get used to it. it's past five years now - she's not able to overcome it.* (P480)

Another participant (P802) pointed out that the ostomy was not so much the limiting factor as other health conditions were at the stage of his life. Comorbidities and effects of chemotherapy and radiation played a major role in his sex life, and he has had to cope with those changes but other elements of his relationship with his wife remain strong.

> *As a result of the chemo and radiation that I had that sort of did the job on me as far as my […] sexual promise was concerned too. […] I've learned to cope with it you know. I learned to deal with it and become sort of matter of fact about it now, there's not much I can do about it. And as my wife says quit complaining you're alive.* (P802)

4.2.3.4 Vigilance and Fatigue. Participants described the effect of the constant awareness of having an ostomy and having to tend to it at any moment, which can sometimes cause them to feel mentally drained over time because they can never 'escape' their ostomy. P802 describes the subconscious thoughts (the vigilance) he regularly has about his ostomy and highlights how having an ostomy is a part of every day:

> *Yeah, like one of the difficulties in dealing with an ostomy is that it's a 24-hour a day thing. It's not something that you can put on in the morning and take off at night. It's something that's with you all the time and it reacts differently to maybe different diets or different activities and […] at night for instance you know when my ostomy pouch fills up when I'm in bed I don't know if it's gas or if it's the real thing so I have to get up and go to the washroom and deal with it and so on. […] it's always on your mind. I mean it's not something that's a dominating thought but it's something in the back of your mind all the time right.* (P802)

Some participants felt and recognized that constant care for their ostomy took a toll on their everyday lives and overall well-being. The constant day-in and day-out of managing their ostomy and dealing with any (physical) issues that arise such as sore skin at the stoma site or side effects of treatments caused them to feel mentally drained over time. P480 described how this felt for him, and how he believes his peers with ostomies sometimes feel:

> *[…] having to go into the bathroom five or six times a day and wash that bag and smell that crap and watch it come out of your stomach and trying to keep the bag clean after a while […] [it's like] going up and getting a needle every day – the first two or three weeks you don't mind it but the third week you almost dreads to go up and this is the same thing with the colostomy and [you go in the washroom] and changes it five or six, washes it out five or six times a day […] You think about it all the time. […] subconsciously, that's the best way I can explain it is subconsciously you're thinking about it all the time […]. I notice myself, sometimes I start to get run down and [when you stop and think about it] for the last three weeks you either got a sore on the colostomy or it's tearing all the time or it gets sore around where the skin is hooked on and you deals with it in the physical [sense] […] you has people not admitting this - but I believe that they're actually wore out trying to keep it clean. That's my opinion.* (P480)

Participant P677 had experienced physical complications with her ostomy that required a lot of care and attention over the years. Similar to P480, she described how her issue with high output caused her to have to tend to her ostomy frequently, and made her not only physically tired but mentally tired as well.

> *My ileostomy [is high-output] so you know I could be emptying it 15 times a day and I would also have to empty it at night and set an alarm to empty it at night because it would fill up while I was sleeping […] You know physically you deal with your ostomy and some people are fine and you know everything goes well and but for the people who are having trouble they're probably having trouble physically, but also mentally.* (P677)

While everyone with an ostomy experienced some degree of vigilance when living with an ostomy, some felt more fatigue from their experience than others, particularly when their condition had been difficult to manage, or when they felt that their ostomy was preventing them from having a normal life.

4.2.4 Sources of Support

Study participants revealed several sources of informational and emotional support they received during the treatment of their disease and in their day-to-day life managing their ostomy, resulting in six subthemes: Partner or Spouse, Family and Friends, Health Care Providers, Peer Support, Ostomy Supply Companies, and Workplace.

4.2.4.1 Partner or Spouse. Most participants (n=9) had a partner at the time of receiving their ostomy, and their partner played a critical role in supporting them through their adaptation. Some partners provided direct support by helping care for the stoma site and assisting with appliance changes, particularly when the ostomy was new, but sometimes for extended periods.

> *I mean I know they show you in the hospital how to change it and how to take care of it but it was like when I came home I just – I really didn't want to do it and my husband did it for me and he did that for me for about almost four years like he did all my pouch changes.* (P781)

Partners were also supportive in public settings. For example, one participant stated that her husband supported her when going out to restaurants by reassuring her to take her time eating and not to worry about things like needing to go to the washroom to tend to her ostomy.

As discussed in the 'Body image' and 'Intimacy' sections, partners were critical in supporting positive body image and confidence by affirming their love and attraction to their partner and stating that their ostomy did not change any of that. For participant P519, her relationship had improved since having her ostomy because her IBD symptoms were controlled.

> *[Before I had my ostomy] I just wasn't feeling well, [sex] was the last thing on my mind, like don't even come near me right. [Now our relationship is] certainly more loving. We're more affectionate towards each other and we ended up adopting two dogs and [...] our life has changed for the better.* (P519)

Overall, partners appeared to be the primary source of support for many throughout their experience of having an ostomy, and participants often stated their partner was understanding and patient during challenges.

> *No one wants to [talk] about the accidents you had. The mess you made in your bed […] and I had a few issues like that and I tell you, if I didn't have my husband I don't think I would have got through it.* (P498)

4.2.4.2 Family and Friends. Participants also discussed how family members and friends supported them. Family members were a strong source of support, particularly in times of illness, as P166 described: "*I got a lot of family. I got four children and I couldn't wish for better. They were 100% behind me. They never missed a day at the hospital.*" Some people were more comfortable being open about their ostomy with their family and friends about their ostomy than others. For example, participant P677 described how her relationship with her friends had not been negatively affected, but she did not talk about her ostomy much with them:

> *Most of my friends just don't really understand because [my disease/ostomy is] not visible to them. It's not like I have some kind of disability that they can see and so most people don't really treat me a whole lot different […]. When people can't really see what's going on under your clothes they just kind of think oh you know you act normal you can't be that sick.* (P677)

Some participants also discussed how their love for family members was a reason to get past the hardships of having an ostomy, accept their reality, and appreciate being able to be there for their family. For example, P357 said "*When times get tough […] you got to step it up, you've got to […] keep yourself together. For my mother's sake as well as my own 'cause I know she wouldn't want me to basically implode right?*"

4.2.4.3 Health Care Providers. HCPs were another source of support for participants. Some HCPs gave informational support only, while others also provided emotional support as well. NSWOCs in particular were seen as lifelines for participants. Many participants had good relationships with their NSWOC and would call them or book an appointment any time that they had a concern.

> *If I need help I contact my [NSWOC] [name], we've had an amazing friendship and if I need help I pick up the phone I call her and I get what else I needs […] Well, I've had to go back and forth to see her because after I had my second surgery I got a dip in my belly, like my belly sunk and I was having a lot of leakage, like from the time I put a wafer on, I wouldn't get through the day, and that became a problem. So I phoned her and she had me come in she worked with me until we found a solution, like she tried a couple of different things with me and the last thing she tried, it worked quite well.* (P267)

Participant P677, who had numerous physical health concerns related to her ostomy, cited her family physician as a key source of support.

> *My main lifeline is my family physician […]. I don't think he's a typical family physician because he's picked up on things with me, like he's the one who picked up on the magnesium deficiency and because of the cramping and – he put a lot of things together that I don't think maybe doctors would have which my symptoms […] He would call me; he calls me pretty much every time I have blood work to check on you know he calls me just to check on me. He's open to new things, he's always looking for anything that might benefit me so when he heard about a surgery for people with hernias on their stoma that it's a new surgery, he, he kept that in his mind and told me about it and other things as well like he's been really kind of like forward-thinking like ways to manage my ostomy like he's made suggested to me. Some of them worked. […] Like he's just, the most amazing family physician that I could've ever asked for.* (P677)

Most participants were not currently connected with a dietitian. Some participants had minimal interactions with a dietitian throughout their time with an ostomy and did not remember much about any support they provided. For those who did discuss the care they received from a dietitian, participants recalled that the dietitian had provided them with handouts about food and diet and general informational support. As one participant described it, "*Basically they gives you a pamphlet with all different kinds of food. Eat this and eat that.*" Some participants discussed how the support from the dietitian was not overly helpful. P498 explained how she was not receptive to advice at the time of dietetic counselling due to her cancer diagnosis and the side effects of chemotherapy.

> *I was very I don't know if it was angry at that time, I didn't think I needed a dietitian. [...] [The dietitians] were very nice, but I wasn't in a good place then I thought I don't need anybody to tell me how to eat.* (P498)

Similarly, P802 pointed out that sometimes the advice given by the dietitian was not helpful because they recommended foods that patients did not enjoy, and it is important to strike a balance between promoting health and enjoying food:

> *There's a lot of things that dietitians for instance recommend that you know as I say people don't like to eat so. It may be good for you and it's alright to recommend it but not everybody likes the same stuff right and if you can combine what's good to eat with something that people enjoy eating well then you got, that's half the battle right.* (P802)

Some participants saw a dietitian not because of their ostomy or the disease that required an ostomy, but due to an additional diagnosis. For example, one person had participated in a group session with a dietitian to discuss diabetes management but found that some of the advice did not apply to dietary needs for ostomy management:

> *[I] came home with information [...] and like one of the things that they recommend [was] that anybody who's a diabetic - if you're looking for something like to munch on it should be popcorn because it don't have so many carbs in it so like I said a lot of people with ostomies can't even eat popcorn.* (P519)

Participant P357 also saw a dietitian regularly for his diabetes, but he stated that because Crohn's disease was so variable, there was not much that the dietitian could do to help.

> *[Dietitians] can give you guidance, they can try and help you but because of the Crohn's and the nature of the Crohn's and the effect that has it kind of throws off what you can do. [...] Again, a dietitian is basically handcuffed by my Crohn's. Basically. I mean, they can suggest stuff but then it's up to me whether I can eat it*

> *with regards to my Crohn's.* (P357)

As illustrated by these quotes, there were several ways that participants felt disconnected from the dietitian and their recommendations. Participant P480 pointed out further reasons why dietetic support was not helpful for him; foods recommended by the dietitians were unaffordable.

> *[Dietitians] tells you to go eat vegetables and fruits and that but realistically I can't afford to eat like I wants to eat. […] I'd like to go buy grapes when you go to buy grapes, they're $5.00 a pound. You try apples well they're not cheap, oranges are definitely not cheap. The food that I would really, really like to try and eat I can't afford it to be honest with you. […] I haven't seen a dietitian now in years. They've got all the brochures and that […] they tells you to eat all the vegetables that you like to eat you just can't afford it.* (P480)

4.2.4.4 Peer Support. The majority of participants received routine support from a formalized peer support group for people living with ostomies, others had attended a support group at least once but decided it was not a good fit for them. Those who regularly attended described positive outcomes such as the ability to relate to and learn from others, and encouragement to have a positive outlook.

> *It gives me I don't know a positive outlook on life, I know everybody there has got an ostomy and they go to the bathroom and they go every five minutes you know they don't think well what is she going to the bathroom some often for, what's she doing?* (P166)

Participants enjoyed the social aspect of the peer support groups and looked forward to group outings and special events. Some participants had gotten more involved in the group other the years and took on administrative duties within the group. Participants explained how people with ostomies understood dietary needs, washroom needs, and typical challenges; people felt at ease in the group, rather than feeling different or abnormal than others. Participant P498 described how one meeting was particularly memorable for her.

> *I found it helped me and I learned [from others]. […] And then we had this guy come once […] and he's very vocal and he tells everything and I was listening to him and I said wow […] this is good because there's a lot of people here including myself who wouldn't ask questions or make suggestions. So that was probably one of the best meetings I found. And then I just started opening up more because of this man and he was having some issues that I had had but didn't tell anybody about.* (P498)

On the other hand, two participants explained how they felt they could *not* relate to others in the support group meeting(s) that they attended, and that they had decided the group was not a good fit for them. For participant P844 this was partly due to how members perceived being "ostomates" as well as her discomfort from the nature of advice shared between members.

> *I went to the ostomy support group that – yeah that wasn't really for me I guess, and I've looked at some things online and like those groups aren't for me either. I don't know why, they just aren't. Like when people ask "how long have you been an ostomate?" I don't think, I find that such a weird question, I guess. [I don't like that language]. Like I have an ostomy but it's not, it's not my defining character. Like most people don't know [I have an ostomy], I don't think anyways. […] I guess I don't really think of it as an identity. And [in] a lot of the [support groups] online they're asking for a lot of medical advice and I'm not going to [give medical advice].* (P844)

For participant P677, she described how she could not relate to other members because she was not having the positive experience that others had:

> *I even joined an ostomy support group here and I stopped going because all these ladies were like laughing and […], I couldn't relate to any of them. Like they were able to drink alcohol, which is something I can't do, they were able to sleep through the night which is something I don't get to do. I often have to sleep sitting up and I just couldn't relate to any of them because they were having a great life since their ostomies and I just am not and so you know there are people out there who this doesn't transform your life and make you live happily ever after.* (P677)

4.2.4.5 Ostomy Supply Companies. Companies that sell ostomy supplies provided a unique form of support to people with ostomies. Some participants cited how the company had provided a lot of information on stoma care and how to clean and change the appliance.

> *They [ostomy company] told me a lot about cleaning it and dealing with it and keeping it clean and keeping it healed. They gave me a lot of advice on skincare, and skincare products. How to wash my stoma, how to rinse my stoma. When you puts it together make sure there's no soap or residue on the skin where the flange got to go on just make sure it's squeaky clean and there's no soap or detergent and make sure there's no perfume in the soap that you're using it could affect the skin when it's covered up.* (P480)

Participants also discussed how the supply companies developed and shared new products to address concerns such as the fit and appearance of the appliance. Company representatives made suggestions on which products to try, provided free samples to participants, and replaced any defective products.

> *[...] if you got any problem with a product [...] say there was a pinhole. They have no trouble sending you a couple more bags to replace it or to give you any advice that they can - like different products coming out.* (P480)

In some cases, a product representative would host information sessions for an ostomy support group or a member of the ostomy support group may even become a representative.

> *I was afraid like I was doing water aerobics before it and then I felt well gee how do I go to water aerobics with [my ostomy appliance [...] well it's different types of pouches you can for different things [...] and I guess it was probably four years, four or five years after my surgery before I went back to water aerobics because I found this little system [ostomy appliance] that I just snap on it's only a little thing. [...] I found out one of the ladies in our support group [...], she's actually a representative for one of the [supply companies] [...] they said well most of these companies have this anything you want to try you can go see your [NSWOC] and they will prescribe it for you and they'll get the company to give you some testers and that's how I got onto to that. [...] I have a dip in my stomach, and I have to fill it in with this paste or paste stick, so the stool doesn't go right under the flange. So now we had a meeting, a ZOOM meeting there a couple of months ago and they were talking about a new product so I'm waiting for them to send me that now so I can test that.* (P498)

4.2.4.6 Workplace. Not all participants were employed at the time of the interviews; some had retired and some stopped working due to their ostomy and overall health. Participants who were employed, or who had worked at some point after acquiring an ostomy, frequently discussed the worries they had at work and the need to have good washroom access. Participant P677 described how her office setting was stressful because she was not able to leave her desk whenever she needed:

> *Yeah, but going back to work was really tough […]. I couldn't leave that desk when I was in that position. I had to get someone else to cover me before I could leave that desk and that phone line, so I did find that hard. I did eventually change positions to one where I could just, you know, if I needed to use the bathroom I got up and went to the bathroom. But it's really stressful when you know you need to go and you can't because you're stuck talking to a client or you're on the phone or you know you just don't have anybody else to cover for you while you take five minutes that you need.* (P677)

One participant delayed going back to work after her ostomy surgery in part due to the concerns she had about caring for her ostomy and managing output at work, but she was able to avail of her Employee Assistance Program to see a psychologist. The washroom at her work did not give her the privacy she needed to tend to her appliance using water from the sink. Later, her workplace did have an accessible washroom, which was a great comfort to her. She also highlighted that the limited number of available sick days and company policies concerned her when she had ostomy issues that prevented her from going to work. In contrast, P519 discussed how her employer was very supportive throughout her history of having IBD, and this helped her feel comfortable adjusting to working with an ostomy, saying, "*I don't have no issues whatsoever and my boss knows, […]. I ended up going in and having surgery, so he knew what I was going in for and that. He's very supportive of that.*"

Overall, the nature of the work (location, working with the public, flexibility) and access to an appropriate washroom were key factors to participants feeling able to work. For people who had a history of gastrointestinal symptoms before their ostomy, this concern was not new, and oftentimes the ostomy partly addressed their issues at work because they actually needed to use the washroom less frequently than before they got their ostomy:

> *Yeah, so [my work] was a combination of office work and home visits [to clients]. So I am happier to now be in a different situation where you do have more access to the washroom. I did worry about like being on the road a bit and you know having to go to the washroom but again I also worked when I was having ulcerative colitis, so it was easier than that.* (P844)

4.3 Interpretation of Findings

4.3.1 Introduction

The participants of this study have all lived with an ostomy for five or more years and they each described coping and self-management skills. While adjusting to their ostomy was difficult in the weeks and months following their surgery, they have accepted their ostomy, and most, but not all, participants appeared to have a QOL that was comparable to their QOL before surgery. Given recurrent challenges, adaptation was an oft-repeated process that required making changes, which were facilitated through various sources of support (Figure 4.2).

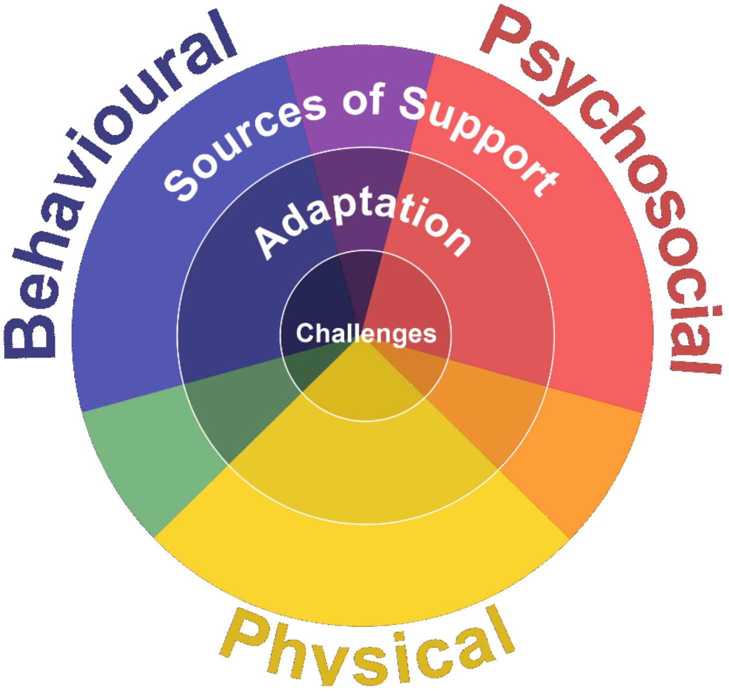


Figure 4.2

Experiencing and Coping with Challenges Model

4.3.2 Experiencing and Coping with Challenges

The challenges, adaptations and sources of support could be physical, psychosocial and/or behavioural adaptations (represented by primary colours yellow, red and blue). Often, there is overlap in the nature of the circumstances of challenges, adaptations, and sources of support during complex changes (represented by the secondary colours orange, purple, and green).

4.3.2.1 Physical. Physical challenges refer to changes in bodily functions that are caused by a person's ostomy, ostomy complications, or comorbidities. For example, nearly all participants had one or more parastomal hernias. Parastomal hernias are the most common complication for people living with an ostomy, affecting up to 50 percent of people (Cima, 2021). A parastomal hernia occurs when the abdominal contents protrude through the abdominal wall due to the incision made during ostomy surgery and the consequent weakening of the abdominal wall (Cima, 2021). Several participants discussed how they adapted to their hernia by using an ostomy belt or having surgery and identified their NSWOC, surgeon, and ostomy supply companies as key supports. Other examples of physical changes include skin irritation, output leakage, and changes in physiological function due to comorbid diagnoses. Notably, our participants described physical challenges related to their ostomy when other comorbidities were present, such as diabetes or psoriasis, and these conditions may increase risk of stoma complications (Bosshardt, 2003; Popek et al., 2010; Zelga et al., 2021).

4.3.2.2 Psychosocial. Psychosocial challenges refer to the mental, emotional, social, and spiritual effects of having an ostomy and bowel disease. For example, study participants frequently discussed the stigma associated with having an ostomy and how their ostomy affected their mental health at various points in time after surgery. Participants described how they coped with mental health challenges by changing their outlook on the situation and focusing on how their ostomy helped them to live with their disease, and/or by seeking therapy. These adaptive strategies helped them realize that having an ostomy did not prevent them from enjoying their life. Most participants acknowledged that their partner was a key source of support while coping with psychosocial changes, and some also received support from a psychologist or mental health nurse. Most participants were also connected with a peer ostomy support group and similar to findings of Byfield’s (2020) study of a similar group, many participants stated that peer support groups allowed them to relate to others and helped them to realize that they were not alone in their experiences and thoughts.

4.3.2.3 Behavioural. Behavioural challenges refer to changes in a person's lifestyle due to requirements of their ostomy management and health needs. To illustrate, several participants described how their ability to participate in activities such as physical activity and social outings changed after their ostomy surgery. Early after surgery, participants worried a lot about experiencing ostomy leaks while outside the home and they restricted their activity while they recovered. Over time, participants developed coping strategies that allowed them to feel more comfortable leaving the house and participating in activities. For example, participants described how they prepared kits with ostomy supplies and extra clothes for their outings, used ostomy products for specific activities (i.e., swimming), or changed their eating schedule. Additionally, participants discussed making dietary changes, such as restricting certain foods or changing the timing of their meals to control their output, in order to minimize issues while at work, at a theatre, etc. Family members and friends were valuable sources of support to help participants feel comfortable during social events.

4.3.3 Experiences of Dietetic Counselling

Most participants had only seen a dietitian while in hospital and/or early after their surgery and did not find dietetic counselling to be overly helpful during their self-management. Participants described how dietitians typically recommended foods to eat and provided handouts after surgery, but dietetic advice was often not in line with participants' needs, capacities, or values. For example, people discussed how dietitians recommended particular foods that participants did not like, did not want to eat, or could not afford. Additionally, dietetic counselling was usually given while in hospital and participants stated that they could not remember their interactions with the dietitian because while they were recovering, they were in pain, on several medications, and overwhelmed. Dietitians usually did not provide long-term support and did not help participants after their initial recovery from surgery. Overall, participants viewed their interactions with a dietitian as *being told what they should eat.* This study suggests that to offer effective dietetic counselling, dietitians must: provide long-term, person-centred care that recognizes each individual's values and preferences, practice joint decision-making rather than one-way recommendations, and provide care at the appropriate times (i.e., during the post-operative stage in hospital and on an ongoing basis while a person is adjusting to their ostomy at home and experiencing new challenges. Person-centred care is defined by Entwistle et al. (2018a) as "an approach to clinical practice that both respects and enables patients as moral agents and collaborative partners whose own perspectives on their lives and how they live them, matter." Therefore, a person-centred approach to dietetic counselling would restore autonomy and respect the individuality of people with ostomies.

Many participants also experienced comorbidities such as diabetes, heart conditions, and celiac disease. Participants' self-management of these conditions complicated their diet changes sometimes made because of their ostomy. The presence of comorbidities also affected the types and amount of health care that participants received. For example, some participants received routine dietetic counselling for diabetes, while others with no comorbidities had no routine follow-up with a dietitian. Some participants identified that dietitians were not knowledgeable about diets for people with ostomies, or that advice given for their comorbidity was in contradiction to what worked well for them with their ostomy (e.g., popcorn was recommended as a good snack for people with diabetes but people with ostomies often avoid it). Dietitians should be cognizant of how comorbidities affect recommendations and identify ways to ensure their counselling is appropriate. For example, group education is often offered to people with diabetes, but may not be appropriate for people with ostomies. Additionally, handouts and education tools may need modification.

Figure 4.2 provides a useful schema to situate the roles of HCPs. HCPs should acknowledge the nature (physical, psychosocial, and behavioural) of challenges, adaptations, and supports experienced and/or needed by people with ostomies. Dietitians can become an important support in addressing the behavioural aspects of living with an ostomy, namely by providing person-centred advice on food choices, food preparation, and nutritional advice. Second, dietitians should recognize that patients with ostomies may need psychosocial and physical support, and where possible, refer patients to relevant sources of support. Dietitians also need to learn how to adapt advice for patients with co-morbidities. Lastly, dietitians, as well as other HCPs involved in the care of people with ostomies, must recognize the need for chronic care management and be available to people with ostomies over time.

4.3.4 Strengths and Limitations

A major strength of this study is that it involved participants of different ages, genders, communities, reasons for ostomies, and ostomy types. Our maximum variation approach allowed us to observe potential differences in experiences related to demographics. Secondly, to our knowledge, this is the first study to explore the experiences of people living with ostomies in NL and our results can directly inform health care and policy in NL.

In terms of limitations, participants of this study have had an ostomy for five or more years and have had a long time to adjust to their life with an ostomy and may have had difficulty recalling their experiences in previous years (i.e., recall bias, recency bias), and this may have resulted in missing information about experiences and/or a change in perceptions of patient-provider interactions. Our sample consisting only of those with a long-term ostomy may be due to recruitment barriers outlined in the COVID-19 Impact Statement, namely the inability to recruit individuals in person in the hospital setting and the disruption of health care services and support groups. Stigma associated with having an ostomy may have also affected recruitment. While the results may provide good insight into the experiences of people with long-term ostomies, the experiences of people with new ostomies may differ. Similarly, the inability to recruit participants directly from hospitals also limited our ability to purposively sample urban vs. rural patients and make comparisons between these two groups.

Additionally, most participants were connected to a formal ostomy support group and their experiences may differ from those who choose not to attend support groups. Lastly, our study did not capture the experiences of people under the age of 40, those who lived in Labrador, or those who did not have a long-term partner. Future research should examine the experiences of people who recently acquired an ostomy, are younger, are unpartnered, live in other areas of the province such as Labrador, and those who do not regularly participate in an ostomy support group.

5.0 Exploring Health Care Provider and Support Group Interactions with People who have Ostomies

5.1 Methods

In this study, we conducted semi-structured interviews with health care providers (HCPs) and support group leaders who care for and support people with ostomies, to better understand their perspectives on food- and nutrition-related concerns of patients, interactions between patients and HCPs (especially dietitians), and the current model of care for people with ostomies in Newfoundland and Labrador (NL). This study directly addresses research objectives:

2. To describe the model of care in NL for people with ostomies.
3. To describe the role of dietitians and their interactions within an interdisciplinary health care team to provide care to people with ostomies.
4. To describe the current practices of dietitians who counsel people with ostomies.

And indirectly addresses research objectives:

1. To describe the nutrition, food, and lifestyle-related concerns of people living with ostomies immediately after ostomy surgery and during ongoing self-management.
5. To describe patients' experiences of dietetic counselling.

5.1.1 Recruitment

We used purposive sampling to recruit participants by contacting physicians, nurses, support group leaders, and dietitians across NL. We obtained contact information for physicians by searching NL's College of Physicians and Surgeons' database, and we found contact information for nurses and support group leaders through the Ostomy Canada Society website. We identified dietitians working in Eastern Health through professional contacts and asked them to identify people who provide care to people with ostomies who may have an interest in the study. Participants who were recruited were also asked to identify colleagues who may be interested in taking part in an interview (snowball sampling).

We initially contacted 46 potential participants by email and sent reminder emails monthly for three months. After three months, we telephoned potential participants if they had not responded to any emails to ask if they would like to participate. We also shared study information on the NL College of Dietitians and the Dietitians of NL Facebook group and invited interested registered dietitians to take part in an interview. Participants were eligible to participate if they were an ostomy support group leader in NL or were a physician specialized in surgery, oncology, or gastroenterology, a dietitian, or a nurse working within any regional health authority in the province (i.e., Central Health, Eastern Health, Labrador-Grenfell Health, and Western Health), cared for adult patients (who have ostomies) in the past five years, and had a minimum of one year of experience working with people who have ostomies. We screened potential participants when they contacted us and sent the consent form to review before the interview, as well as a brief demographic questionnaire (Appendix G). Interviews were conducted once we received consent.

5.1.2 Data Collection

We used a semi-structured interview guide of open-ended questions to ask health care professionals about dietetic counselling and interprofessional collaboration as a health team (Appendix H). Questions were chosen based on current literature and were intended to help us understand the health care team and community partners, interactions and relationships between care providers and patients, as well as the health system's support for patient self-management. We asked participants about their role in caring for and supporting people with ostomies, related goals and length of care, common concerns, barriers to care, and how they worked within a health care team. We asked probes (i.e., probing questions) to elicit additional detail and clarify responses. We used member checking to ensure we understood each participant's meaning by summarizing and stating the participant's responses during the interview and allowing the participant to correct or clarify responses (Candela, 2019; Hadi & Closs, 2016). At the end of each interview, the participant was given the opportunity to provide additional comments and ask questions.

Interviews took place from October 2020 to May 2021 by phone or via WebEx videoconferencing, depending on the participant's preference. I conducted all interviews and recorded interviews with a voice recorder or local WebEx recording. I took brief notes throughout the interview. Interviews lasted 23 to 120 minutes.

5.1.3 Analysis

I or a member of Memorial University's Health Research Unit transcribed the interviews. I compared transcripts to the original recording to ensure the accuracy of the transcription and to incorporate cues (e.g., sarcasm, humour) indicating the character of what was spoken. I created pseudonyms for each participant. All quotations are in the English dialect spoken in NL and include many local and idiomatic expressions.

I kept a journal of field notes, written following each interview to record thoughts and perceptions, highlighting emerging ideas and noting any adjustments to the interview guide (Hadi & Closs, 2016). I also made notes throughout the coding process to facilitate reflexivity and to identify potential themes. Additionally, I referred to my field notes as I carved out the study's narrative to ensure my initial perceptions lined up with my analysis (Atkinson, 2007). Using a pragmatic approach, I also recorded my reflections on participants' experiences and how they related to the organization of health care and the role of dietitians, while noting any potential actions to mitigate challenges of health care providers (Allemang et al., 2021; Giacomini, 2010).

My supervisor, Dr. Mathews, and I independently reviewed five transcripts (of interviews with various types of HCPs) and highlighted recurring words, concepts and key themes. We then met to compare and discuss our individual codes, integrated, described, and defined the individual codes through consensus, and described their relationship to one another until an integrated coding template was created (Green & Thorogood, 2018). I used the final version of the coding template to code all of the transcripts using Nvivo software.

We took several measures to ensure trustworthiness and provide information to other researchers interested in transferability by maintaining an audit trail throughout the study by storing recordings and all versions of transcripts and coding templates (dependability and confirmability), documenting coding differences and their resolution (dependability and confirmability), and coding thick quotes to ensure quotes were used in consideration of context (credibility; Green & Thorogood, 2018; Kuper et al., 2008).

5.1.4 Ethics

Ethics approval was obtained for this study (Appendix I). Our proposal was approved by NL's Health Research Ethics Board (HREB; Reference 2020.060) and the research review committees of each regional health authority in the province.

We informed participants that while pseudonyms would be used and measures would be taken to protect confidentiality when selecting quotations for reports, participants may be identified by deductive disclosure due to traits making them identifiable, such as unique work experiences or the small number of professionals who work in ostomy care within the province. Participants were asked to provide consent by reading a consent form and providing verbal consent. Each interview began with a review of the background of the study and confirmation of consent, and I noted that the participant may withdraw from the study at any time.

All data were password protected and I accessed the data from an encrypted hard drive. Only the researchers involved in this study had access to the data. The study data will be destroyed five years after completion of the study, as per the university's regulations. There are no identifiers attached to any information presented within this dissertation. We will make a summary of our findings available to the Ostomy Canada Society so that participants can be informed of the results.

5.2 Results

We sent invitations to 46 HCPs and ostomy support group leaders and 22 people expressed interest in the study. One person who was interested in the study declined an interview due to their ongoing work commitments and the added stress of a COVID-19 outbreak. We interviewed 21 HCPs and ostomy support group leaders who had experience caring for and supporting people with intestinal ostomies.

The 21 participants included eight dietitians, seven physicians, three nurses, and three support group leaders (Table 5.1). Participants worked in a variety of settings such as rural or urban communities, and inpatient and/or outpatient care. Most participants cared for patients in the Eastern Health Region (n=15) and identified as women (n=15).

Table 5.1

Demographic Characteristics of HCPs and Support Group Leaders (n=21)

Characteristics	n	Characteristics	n
Profession or role		**Years in profession**	
Dietitian	8	1-5 years	3
Nurse	3	6-14 years	5
Support group leader	3	≥ 15 years	13
Physician	7	**Years of ostomy-related experience**	4
Gender[1]			
Women	15	1-5 years	7
Men	6	6-14 years	10
Region		≥ 15 years	
Eastern	15		
Central	3		
Western	3		

1 – Gender was self-reported using an open-ended question, only two gender types were identified by participants.

We identified four major themes that were recurring ideas across the interviews: Model of care, Patient concerns, Team functioning, and The Dietitian (Table 5.2).

Table 5.2

Organization of Themes and Subthemes Within Health Care Provider Study

First-Level Theme	Second-Level Theme	Third-Level Theme
Model of Care	Role of the Physician	
	Role of the Nurse	
	Role of the Dietitian	
	Role of the Support Group Leader	
	Variation Based on Underlying Conditions	
Patient Concerns	Stoma Care	
	Management of Ostomy Appliance	
	Management of Ostomy Output	
	Nutritional Needs	
	Sex and Intimacy	
	Financial Considerations	
	Lifestyle	
	Coping and Mental Health	
Team Functioning	Communication and Interactions	Liaising with Support Groups
	Barriers to Care	Limited Follow-Up
		Lack of Interdisciplinary Care Settings
		Geography
		Mental Health Resources
The Dietitian	Training	
	Sources of Information	

5.2.1 Model of Care

Model of Care refers to how care is structured in the health care system, including a description of usual team members, roles of HCPs, and which HCPs see the patient at various points of care and locations (Donabedian, 1968). While a person is recovering from ostomy surgery in the hospital, routine team members include the surgeon, a nurse specialized in wound, ostomy, and continence (NSWOC), a dietitian, and the nursing staff. People with ostomies may see other HCPs during their hospital stay depending on their individual needs. After discharge from the hospital, people with ostomies may be seen by community health nurses and/or NSWOCs and may be connected to an ostomy peer support group. Model of Care has five subthemes: Role of the Physician, Role of the Nurse, Role of the Dietitian, Role of the Support Group Leader, and Variation Based on Underlying Condition. The first four subthemes highlight the roles and timeline of involvement of HCPs and support group leaders. Variation Based on Underlying Condition describes how the model of care varies depending on the diagnosis of the individual receiving care.

5.2.1.1 Role of the Physician. Of our study participants, physicians (i.e., oncologists, gastroenterologists, or surgeons) were usually the first point of contact for people who required an ostomy. The physician's first visit typically involved discussing treatment and surgical options for the patient's underlying disease. For some patients, this may be the first time that they hear about an ostomy and learn about how it functions.

> *So, most of my stuff is pre-op and it involves sort of discussion of what the treatment of their disease is. And that [treatment] would potentially or definitely involve some kind of stoma and obviously with an individual case you get into a little bit of individual detail. But I'm usually the one introducing the idea or just about at the beginning, the first person introducing the idea of them having such a thing.* (P3)

A surgeon's first visit would also include a discussion of possible complications of the surgery and what to generally expect. During this time, the patient would have the opportunity to ask questions about the procedure and the surgeon would ask for consent to proceed with surgery:

> *So, most of my discussions are based around the indication for and the possible complications of the operation. A stoma may be part of that operation [but] it's*

> *not necessarily the focus of our visit. […] Then during that consent process, [I give] patients the opportunity to ask questions that they might have and then [point] them towards whatever resources we have available for them in the time prior to their procedure.* (P4)

The general discussion of the initial visit would vary depending on whether the surgery was previously planned or on an emergency basis. If the surgery was happening in an emergency situation, the discussion may be quite short and there would be less conversation about how an ostomy functions and what to expect after surgery.

> *So, the two ways we would be bringing patients to the operating room would be either on an elective basis, for example they'd be diagnosed with a cancer - this is the surgery we must do to take the cancer out, or on an emergency basis. And the conversation is actually quite different depending on the setting. When we meet a patient in clinic for example, and we have diagnosed them with something like a cancer or they've got really bad Crohn's [disease] or something that requires surgery, […] we kind of come up with a game plan. We've had some time to think about it, this is what we're planning to do to operate. […] When we meet someone in the emergency room though, a lot of the time either they're sick or […] everything around their health is not as optimal. The conversation is often a lot more [like] "we probably will most likely be giving you a stoma" or "we'll try not to but there's a good chance that we will have to." And […] actually, there's not a whole lot [of] discussion around what that means, about having a stoma. [It] is not actually as involved pre-operatively, especially when it's happening in an emergency setting because the situation is often "you're going to need this like you're very sick and this is sort of what you need", "this is what we can offer you" and then the discussion of actually taking care of the stoma often starts to take place afterwards.* (P1)

In non-emergent cases, physicians highlighted their role in explaining how an ostomy functions and what to expect for recovery and life with an ostomy. The discussion involves answering patients' questions about what it is like to have an ostomy and how it will affect their day-to-day life:

> *Patients often have questions about how the ostomy is going to function. And I would say anecdotally, the vast majority of my patients think that they're going to have functional physical limitations because of their stoma. So that's the first thing they ask me, they ask me, "well I'm not going to be able to go on the bike, play hockey, do whatever." So, we often spend a fair bit of time discussing the*

> *physical sort of side of the stoma and what they can expect postoperatively.* (P4)

Some physicians also noted their role post-surgery while the patient is waiting to be discharged from the hospital. Physicians described how they support the patient to accept their new normal and take control of their ostomy and self-manage at home:

> *So, patients understand why they've gotten their stoma and sometimes stomas are permanent, sometimes they're temporary [...] ultimately you want a patient that's able to manage their own stoma independently if they have the physical abilities to be independent and stuff. So, you need to equip these people with as much as they can derive from their treatments so that they'll be successful in their own home environment, and not require other people to provide care to them. Some people aren't ever able to take on their stoma care but for the most part, most are. So, the educational component and positive reinforcement is vital for people to have success with that.* (P5)

Physicians also noted their role after the patient's surgery and during follow-up clinics; they monitored patients for issues with their ostomy and symptom management:

> *We do a less direct role in terms of actually advising [patients] on what kind of food to eat and things like that, but when there's issues such as high output ostomy [...] we'll be the ones that are prescribing the medications to try to slow down or change things about that. Or if they need to go back to the [operating room] for revision of their ostomy in any way that would be us as well.* (P1)

After the surgery is performed, the surgeons are primarily concerned with things like healing and infections and other potential complications.

> *The main thing we're concerned about initially after the surgery is it's healing well, is there any signs of ischemia, if their surrounding sutures holding into the skin are intact, make sure there's no breakdowns that could create wound healing problems or infection or abscess inflammation problems. So that would be the main hands-on things that we would do post-surgically and in addition to the nursing staff and stoma care nurses if they have any concerns, they'll bring it to our attention so we can assess it.* (P5)

Physicians explained how during follow-up care, they monitor the patient's pain, diet, and ostomy functioning. Once a person has been discharged from the hospital, they are seen by a physician in a follow-up clinic six to eight weeks later and then consulted as needed.

> *The checkmarks for the person to be discharged from the hospital from our perspective is that their pain is under control, […] they're at a reasonable diet and a reasonable activity level, that they could take care of themselves at home or whatever their home setting might be, and that they are independent with their stoma or someone in their house is willing to […] help them with their stoma. […] That's when we discharge them, […] then we follow-up with them in the clinic usually at 6-8 weeks afterwards and it's more to see that their wound is healed up nicely, that they're coping well, and that their stoma is working well.* (P1)

5.2.1.2 Role of the Nurse. Nurses, usually NSWOCs when available, aimed to visit patients pre-operatively for their first visit and mark the site for their stoma. Stoma site marking involves the nurse working with the patient to identify where the stoma should be placed to prevent discomfort and issues such as leakage. During this visit, nurses would begin to educate the patient and answer any questions about what to expect:

> *Ideally, I would see them preoperatively, I don't always but I like to get them pre-op if I can 'cause then I can mark the site for the stoma. And generally, when I mark the site for the stoma there's a lot less complications, because sometimes they get put in places that they shouldn't be and then it causes pinching, issues, and things like that. So ideally, I see them pre-op and if I do see them pre-op, I'll answer all their questions and I give them all the information […] so [patients] have a chance to review it and things like that before their surgery.* (N1)

Participant N2 discussed how an ideal first visit includes time to get to know the patient. Some patients are more engaged than others during a pre-op visit, while others are overwhelmed:

> *Well, if we're not too crazy busy we generally have time to sit with them and chat with them and discuss things with them. So mainly yeah like in the pre-op setting sometimes we could spend an hour depending on the patient […]. It seems like those who are a little bit knowledgeable about it will ask a lot of questions and want some concerns addressed. Those who have no idea what this is are looking at you without even hearing what you're saying. They might be listening, but they just might not be getting what you're saying until they see you in the post-op setting and then they're like "whoa this is what it is."* (N2)

Nurses also discussed how they routinely cover a comprehensive list of topics to educate the patient on how an ostomy should appear and function and how patients can self-manage an ostomy at home. Participant N1 explained how some topics may be discussed directly with the patient during their visits, while other topics may be covered in reading material provided to the patient:

> *Topics-wise, I do have a package done up essentially for patients which covers anything from travel with an ostomy, you know resuming sexual activity, like sex and love and relationships for example with an ostomy, of course, healthy eating with an ostomy or dietary advice for example like pamphlets or handouts and things […] The fact that they can disability tax credit with an ostomy, […] I need to figure out essentially postoperatively if they [have insurance or] would they qualify for a program. […] There's a lot of information in the package but how much we physically go over at the time is more about like you know how do you clean it, how do you change it, how do you empty it […] — what to expect like, what it should look like, what would be a complication, when to call […]. It's […] everything you need to know to get home, safely, and manage for a few weeks until you come back.* (N1)

Nurse participants explained how they also play the main role in assessing which ostomy appliance and products would best suit a patient. Nurses review the features of different products to help patients find a product that suits the patient's needs and lifestyle:

> *We help determine what product works best for them and we prescribe the products [that are] necessary. We write prescriptions for whatever it is that they want to go with, whatever pouch, whatever wafer, any accessory products. A lot of people are not aware of all the different types of products that are available to help them with issues that they're having. So [we spend time] educating them on the different products, providing them with samples to try so that we can determine what is going to work for them.* (N3)

Participants also discussed how nurses assess how a patient feels and their ability to cope with changes after learning what to expect with an ostomy.

> *When we […] discuss with the patients [about their ostomy], we always say to them "this is what is expected with ostomy care" and you know "how do you feel, like how are you able to cope with this?" "[Who] do you have available that can come in and learn about the ostomy care and help you if need be?"* (N2)

Similarly, nurses frequently discussed the need to build patients' confidence to self-manage. Participants stated that supporting patients by addressing questions and concerns with education and reassurance was a vital part of their role.

> *I mean we're always educating people on ways to get through their day without having mishaps. So, if someone is worried about mishaps at work, you know we'll educate them on emptying their bag more frequently, make more frequent bathroom visits to check to make sure everything is okay, so you don't end up with accidents. So basically, it all comes down to what they want. […] we just provide whatever education is necessary to help them through that.* (N3)

Nurses discussed how they continue to see patients throughout their stay in the hospital. The number of nurse visits varies depending on the needs and independence of the patient and the nurse's availability. Barring complications, the length of a patient's hospital stay is largely dependent on their readiness to care for their ostomy at home. N2 explained, *"They're in for really as long as they need, like some patients might only need two teaching sessions, some might need five [before feeling ready to care for their ostomy at home].*" Some nurses discussed how follow-up care often involves family or caregivers, so that others know how to care for the person if needed, but also to be supportive and able to assist the patient during their transition to self-management of the ostomy.

> *Ideally, after surgery I'd get the patient's spouse or partner or friend or somebody […] in with them to do the teaching as well 'cause usually the patient [is] quite sick and they're taking medication or whatever, and they don't always remember everything I'm saying you know what I mean? So, I try to teach at least one other person or their family or whoever I can get there for the session so when they go home, they have [support]. Usually, the goal is to self-manage and take over their care, but usually for the first couple weeks you know it helps to have a family member or someone to help.* (N1)

Some nurses held routine clinics where patients receive follow-up care. Typically, people with ostomies were seen by a nurse four to six weeks after surgery.

> *I have an ostomy clinic at the hospital and then I do follow-up, so I would do say like a four-to-six-week post-op follow-up. […] patients can self-refer, so any ostomate in the community or in the [region] can call or book an appointment to*

> *be seen in clinic.* (N1)

Nurses may continue to see patients while they have an ostomy, or the patient may only return for care if an issue arises. Follow-up care may include regularly scheduled visits or be sporadic, depending on the patients' needs and preferences.

> *They [my patients] may have had [an ostomy] for two years, they may have had [an ostomy] for twenty years. But it's people who might be running into issues with skin problems that they've never had before, they'll end up having issues with leakage, things like that. If they gained weight or lost weight or if they have other illness on the go and all of sudden their stool consistency changes, and they're not used to it.* (N3)

Participants also mentioned that they will provide patients with information regarding follow-up care that is offered by most ostomy supply companies. These programs typically include remote access to a nurse and therapist.

> *I also set the patients up for discharge programs like the three main companies that we use all have really good discharge programs and essentially, they send a pile of supplies to the patient's house post-operatively. And then a lot of them have NSWOC nurses on staff and they call and follow-up with patients and patients call there and follow-up as well for an extra resource.* (N1)

5.2.1.3 Role of the Dietitian. All dietitians discussed how they reviewed general needs for good nutrition and healing during the initial visit. Participants mentioned various components of their initial assessment such as reviewing lab work and typical eating patterns. Most dietitians first saw their patients after their ostomy surgery:

> *Well [I] start out with just the general nutrition in terms of healing, […] I then start to pinpoint because most of them realize that there's going to be some changes to their diet, or they assume so. So, then I'll start to kind of hone my teaching towards those specific questions, and especially with [people with] ileostomies [I make] sure they understand the importance of drinking enough fluids, making sure [they've] got enough of those electrolytes like the sodium, potassium, and whatnot. And you know they're going to ask if there are things that [they] have to avoid.* (RD1)

One dietitian, RD4, saw patients before their surgery in an outpatient setting. In this case, the dietitian was able to review what to expect regarding diet after their surgery and answer any questions the patient had.

> *I often see people prior to having their surgery so like if they're having upfront chemo and radiation, I may see them before they have an ostomy and so sometimes, I'm providing education beforehand to kind of prepare them for it. And then or other times I'm seeing people for the first time, and they already have an ostomy. [...] So if I know that somebody is going to be having the surgery you know in the near future, I do ask them if they would want me to review the information with them ahead of time. Sometimes that can help them to wrap their heads around what to expect, maybe start some of the planning of what kinds of foods they want to have available. Or if they're not ones who normally eat three square meals a day, maybe start working towards eating in a pattern like that that might be a little bit better for them digestive-wise.* (RD4)

In terms of the focus of education, dietitians pointed out the need to discuss recommendations for good ostomy functioning to prevent issues such as blockages, high output, dehydration, constipation, gas, odour, etc.

> *We talk about general healthy eating guidelines, we talk about foods that they would need to avoid to help prevent complications with their ostomy, such as stoma blockage risks or excess gas production, excess odour production – they would generally be the main topics.* (RD2)

Some dietitians also noted that food restriction and emotional concerns related to adjusting to life with an ostomy were frequently discovered during dietetic counselling. For example, RD3 pointed out that many of their patients would restrict their intake to minimize their ostomy output so that it would be less disruptive to their daily activities:

> *We get a lot of patients who don't want to eat all day because they don't want their ostomies to [have output] while they're at work. They just want [the ostomy] to not do anything. So, there's a lot of manipulation with how people eat on their part, [they] just to try to manipulate what their ostomy is doing because a lot of people just don't want anything to happen with it. So, I think as far as the good patient care goes it's just [to] identify whether it's just a mechanical issue or if it's an emotional or mental hang-up with regards to adjusting to actually having the ostomy. And ultimately just trying to find a way to make sure that you can get them to be well-nourished, either to recover from surgery or stay strong through radiation or chemotherapy, and just have good health in general.* (RD3)

Dietitians described how the duration of follow-up care depends on several factors such as length of hospital stay, health complications of the patient, the position of the dietitian, and the needs of the patient. Dietitians who worked in inpatient settings often provided their contact information during their last visit during the patient's hospital stay and discharged the patient from their care. Sometimes dietitians would only see an ostomy patient once during their hospital stay.

> *So, every patient with an ostomy whether it's an ileostomy or colostomy I would receive a referral on, and I'd basically do a nutrition education session with that individual, usually it's a one-time instruction. […] We have one set of guidelines for an ileostomy, one set of guidelines for colostomy and that would be it. […] So usually when I see them here that's the last time, they will need any nutrition education. I do always provide them with my phone number so if they have any questions or concerns once they're at home. If they're having any trouble tolerating diet, they can certainly give me a call. […] they rarely do have to call with a follow-up question.* (RD2)

For the dietitians that saw patients in hospital only, it was rare to hear from patients afterwards, and the dietitians were no longer involved in any follow-up care.

> *Now I put my name on the information I give them so they can always call me if they need me, but no one ever does. It seems to me that they transition fairly easily unless they're just not complaining I don't know.* (RD7)

Dietitians who work in both an inpatient and outpatient setting said they may see patients after they are discharged from the hospital if the dietitian had concerns about the patient.

> *I'll be seeing them for the duration of their time in the hospital and then depending on their care and needs when they go home, I will also include with some of the literature that I'm sending them home with my name and telephone number on a business card so that they are welcome to call me at any time. If I really feel that there's more to be taught or I feel that there might be some issues when they go home, I will book them a specific appointment to come back and see me in my office.* (RD1)

Participant RD6 typically followed up with patients in an outpatient setting to ensure they had a healthy eating pattern, one that was not too restrictive or limited because of their ostomy and worry about its functioning.

> *So, I think it's important that they have follow-up with the dietitian to make sure they are still getting what they need, but also to make sure that they are not developing this negative relationship towards food that could have them into something more serious like an eating disorder, or disordered eating, or malnutrition.* (RD6)

Dietitians who conduct outpatient follow-ups explained that may see patients several times throughout their care, particularly if they are undergoing further treatments or surgeries. Many dietitians commented that once they felt a patient was eating well and there were no major nutritional issues or concerning eating patterns, then it may be an appropriate time to cease follow-up care.

> *If they're on radiation typically we'll see them probably every week or 10 days so that's actually a really good opportunity for us to have some good frequent follow-up as well. Not everybody comes for radiation so sometimes you might only have follow-up every few weeks. Really, it's kind of case-dependent but like I said ultimately our [goal of] good patient care […] is to try to get these patients back to a normal well-balanced diet as much as possible. […] once I feel like that's been taken care of and they're back to baseline, everything is stabilized whether it's the side effects, their symptoms, or their weight, or their nutritional status – once that's back to where I'm happy with, I may offer them the opportunity to curtail any follow-up. But we never ever tell anybody "Okay well you're done here." As long as they feel they need that support, we're always there.* (RD3)

RD5 echoed others' sentiment that patients could continue to have follow-up appointments if they felt like they needed it and that they could always call to reach them with any concerns they might have.

> *The follow-up could be a month later and it could be like once a month or you know depending on the patient. If somebody had a lot of issues or concerns like they can call me as often as they want. So, like if they need weekly phone calls, they can have weekly phone calls. If they are doing well and once a month is good for them that's fine and there are times when once we've gotten to that point where things are settled out you know they've adjusted, […] Between myself and the patient we kind of decide if it was time to discharge them, but even after discharge I welcome patients to call me anytime.* (RD5)

5.2.1.4 Role of the Support Group Leader. Typically, leaders would meet most patients during the patient's first time attending a support group meeting. For example, patients may become a member after hearing about it from an HCP or while purchasing their ostomy supplies. In some areas, support group leaders may meet patients in the hospital or shortly after surgery through a peer support visiting program supported by Ostomy Canada. Participant SGL1 described the program:

> *So, this program is under the Ostomy Canada Society wherein these ostomy visitors are trained, and they are ostomates, they have ostomies themselves. […] So, I think [the program] is a vital support for them [people with new ostomies] because going home they are by themselves, and […] again it is [with] the permission of [the] patient.* (SGL1)

Some support groups also had a program in place where a person who has a long-term ostomy may visit a patient who has a new ostomy to offer them support and reassurance.

> *We visit homes [me and my spouse], if I'm going to see a patient my age [my spouse] will just come along and sit down and talk to the [patient's spouse]. Just to give [them their] point of view and what happened [when I got an ostomy]. So, it's just moral support really and [it] just leads them in the right direction [of] where to find things and how to get things.* (SGL3)

The primary focus of the support group leaders was to host meetings and facilitate conversations where people with ostomies could openly talk about their ostomies and come to terms with the changes in their lives. As participant SGL3 said:

> *Our approach, our major concern is that the client accepts it. […] there's nothing wrong with [having] an ostomy. There's no disgrace to it. You're on this earth. I'm here because I got an ostomy. If I hadn't gotten an ostomy, I'd be dead now.* (SGL3)

Participant SGL2 further explained that sometimes people feel like they should not talk about their ostomy: "*I think it's a taboo thing for most people and I think […] it needs to change, that it shouldn't be taboo.*" Participant SGL3 recognized this issue as well and commented on how they help encourage members to feel safe to talk about their situation:

> *The first thing we say in every meeting is "what's said in this meeting stays at the meeting." […] who you see at the meeting stays at the meeting, because some people are just that private, they don't want [information shared] outside […]. If they were there or not, what they talked about or what we talked about – it stays at the meeting.* (SGL3)

Participants explained that support group meetings are very member-driven. Members decide what they would like to discuss, how meetings take place, and choose guest speakers.

> *So, you know we work - our meetings are mainly dictated to us by the members because it's what they want to hear. It's not what I want to hear, or our executive wants to hear – it's what the members want to hear.* (SGL3)

Topics of discussion varied by group. Members may talk about skin integrity concerns, hernias and complications, the disability tax credit, products, etc.

> *Normally we've been discussing like how drugs interfere with an ostomy, how different foods can interfere with an ostomy, what type of products [exist], what's new out there on the market... We usually try to have a guest speaker. So [we talk about] anything that pertains to an ostomy.* (SGL2)

Participating support group leaders viewed support groups as an important part of supporting individuals to continue the lifestyle and activities they enjoy (i.e., reaching their personal goals). For example, participant SGL1 shared how they offered reassurance to an individual who was worried about going back to work:

> *I said do you have any questions and stuff and then he said "well [I'm] really getting depressed about going back to work" and I said why? […] [He feared] going back to work and he loves [work] dearly [but] then at the same time the fear of going to the bathroom and emptying then and the fear of gas, and the fear of smell, and he's not alone in the office right.* (SGL1)

Through participant SGL1's reassurance and learning from others who had an ostomy, the individual was less worried and returned to work with more confidence.

The meeting schedules of support groups varied, particularly during the time of this study due to the interruption of in-person meetings due to the COVID-19 pandemic. Members meet as they choose and may plan special outings or holiday events. Participant SGL1 explained the significance of special outings and events:

> *So, considering too that you know, you have a special bond together, and every once in a while, I think it's a good feeling to make more connection and enjoy [something different from regular meetings]. It's a different atmosphere, and [it's good to] enjoy the spirit of Christmas or go to [a scenic community] just for the sake of having fun and have to see [the community], [...] and [after an outing] I cooked turkey soup for everybody and sandwiches and all that stuff and it's worthwhile right. It's a part of connection.* (SGL1)

Participants stated that members are welcome to attend meetings for as long as they like and are encouraged to remain a part of the group for support while having an ostomy.

> *I guess we chuckle a lot about things that happen, [like] waking up covered in waste and how you manage it and how you do it, even down to what type of mattress protector works better than others – like I said it's actually complicated. It makes life a little tiny bit more complicated but the one thing I have discovered [is] that we [group members] all learned to chuckle.* (SGL2)

5.2.1.5 Variation Based on Underlying Condition. Patient care varies based on the patient's diagnosis and disease status which can often dictate where and how patients receive care. Participant P1 explained:

> *Like if it's cancer they'd be seeing the rest of the oncology team, the medical oncologist things like that. If it's Crohn's [disease], they'd see the gastrointestinal specialist. In terms of just like the decisions to see other doctors, [they] would be more disease process driven as opposed to the stoma itself.* (P1)

Although the model of care looked quite similar while a patient was admitted to the hospital, it varied during follow-up care depending on the patient's disease status. For example, patients with non-cancerous diseases like inflammatory bowel disease (IBD) were followed by a gastroenterologist. Physicians caring for people with non-cancerous diseases tend to see patients one-on-one and do not routinely have other HCPs involved in their clinics, but they may reach out to the surgeon or NSWOC if needed.

> *[If patients have] issues with their stoma which I, I'm not very good at that because I'm not the surgeon so I didn't put it there, but you know sometimes there might be surgical revisions that need to be made. Thankfully, there's some nurses here who can often help out with some of that stuff, and they might even be more familiar with it than I am like [name]. So, I've called on [name] a lot in the past when I needed things dealt with, you know if there was a little bit of superficial bleeding or whatever and they need some silver nitrate or whatever, she was great assistance there.* (P7)

In cancer care, a variety of HCPs provide care over the course of a patient's treatment.

> *I work with the family physician as well [...] so usually they work with me that's one. Number two is the nursing group which includes two different kinds of groups. One is the chemotherapy nurses and the other one is the nurses in the clinic and the number three is the dietitian group and [number four] the pharmacist.* (P6)

However, participant P6 pointed out that there are some patients with an ostomy due to cancer who may not be followed by a dietitian after discharge because they do not require further treatment and will not be followed at the cancer care centre.

> *There are some patients who have ostomies, and they don't come to [the cancer centre]. Somebody who has an early-stage cancer for example, a stage one of [rectal cancer] and they [had] an abdominal perennial resection – they're not going to come to cancer clinic, they are just followed by the surgeon. Like those patients who do not require chemotherapy/radiation therapy.* (P6)

In many cases, the physician's focus may not be on the ostomy itself, but instead on the disease being treated, the treatment regime, and any potential side effects of the treatment. In the case of cancer, one physician noted:

> *The [common] cause of an ostomy is colorectal cancer [...] and for many of those patients, they end up [with a] proximal ostomy such as an ileostomy and most of the medications that we use they are antimetabolites, so they increase the risk of diarrhea. So, then it becomes kind of a multipronged approach how to control diarrhea starting from the type of chemotherapy chosen, to [how to] monitor side effects and how to adjust diet and what antidiarrheal medications to be done.* (P6)

Another physician commented on how their work with a patient to ensure their IBD is managed:

> *My main focus is to ensure that their IBD is under control, and I guess then with all patients with IBD we want to make sure their nutrition and lifestyle [are] good. So, you know [I'm looking for] any evidence of nutritional issues [...] I'd be looking at blood work and ensure they're not becoming anemic and they're not iron-deficient or that their B12 is going low, and that their electrolytes are stable, and they're not ending up in renal failure or dehydrated or anything like that, [and] the amount of fibre they take in their diet.* (P7)

Dietitians are routinely a part of the cancer care team, are easily accessed by patients with cancer, and other HCPs are familiar with their services and when to refer patients to them. These dietitians often work with NSWOCs, oncologists, nursing staff, radiation therapists, and pharmacists. There are outpatient dietetic services available for patients with ostomies for non-cancerous diseases, but they seem to be less well-known or routinely used.

> *Now our patients who are cancer patients and are being treated and seen at the cancer centre do have access to dietitians because we have them here. So, we can refer them to them, and they further discuss [nutritional concerns] with them right. [...] Yeah, I don't know of any in the community that works with [other patients who do not have cancer]. They may be out there but I'm not aware of them.* (N2)

A physician also commented that there is not easy and timely access to dietetic services pre-operatively in the community setting.

> *That [dietetic teaching] will almost always be done in the inpatient setting largely because I often don't have access to it preoperatively and that's because they aren't excellent community resources for this – just from a timing perspective, especially for my cancer patients. But while they're in hospital all these patients are consulted to the in-hospital dietitian. [...] It [arranging an appointment with a dietitian in the community pre-operatively] would be like another step in the process of before next we have to do this, and it usually just isn't realistic. Again, if we had [pre-op teaching] where we could get a cohort of patients in every week or something, I think a dietitian would be an asset to that.* (P4)

The occurrence and frequency of follow-up visits also varied by disease status. Dietetic follow-up for patients with a non-cancerous disease was seen as rare, whereas follow-up with patients with cancer was routine. A dietitian who routinely sees patients with cancer commented on how they see patients for routine follow-up during their treatment, and the perceived benefits:

> *Yeah, we do things a little bit differently here probably than a lot of other areas so yeah it might be a little bit exclusive to just cancer care in particular, but I find it's really liberating to us because we don't have anybody saying you know you got to get them in, you got to get them out. We can kind of use our own professional judgement to decide when a patient is ready to transition to purely self-care.* (RD3)

Physicians explained that if a person has a disease that is not well controlled, they will receive frequent follow-up care during their treatment, and it may be more fluid, as physician P6 said "*our work [is] like call when you need us as well rather than just come back in three months."* The duration and frequency of follow-up care by physicians vary primarily by the patient's disease status and any complications they may have with their stoma, as seen by the following excerpts:

> *So, if they are cancer patients, I'm generally involved in their care over at least [a] five-year period before they're discharged entirely. […] If it's IBD that's very variable because I'm not managing the medical aspect of their IBD, so you usually follow [them until] their surgical issues are resolved and then they're followed by the gastroenterologist. Should they have further surgical issues maybe they get referred back to [me]. If it's [non-cancerous] disease for which they had a stoma and for which it is possible that the stoma could be reversed, then you generally follow them throughout that time period until you have reversed them, […] [So I follow them for] a minimum of months [to] a maximum of many years.* (P2)

> *For the [IBD] patients I'm probably seeing them fairly frequently like every maybe six months and in some cases maybe even more frequent. […] if they got to the point where they needed an ostomy, they're probably you know on the sicker spectrum of IBD so they're probably even more frequent clients in clinic.* (P7)

5.2.2 Patient Concerns

Participants identified concerns that were frequent topics of discussion during HCP and patient interactions. The nature of concerns varies in urgency, severity, and complexity. In addition to concerns about disease-specific care and surgery described above, participants identified the following issues: Stoma Care, Management of Ostomy Appliance, Management of Ostomy Output, Nutritional Needs, Sex and Intimacy, Financial Considerations, Lifestyle, and Coping and Mental Health.

5.2.2.1 Stoma Care. This subtheme relates to the health of the abdominal stoma itself and skincare around the stoma. Participants described how people with ostomies have to continually monitor the health of their stoma (i.e., colour and size) and care for the skin around their stoma to prevent irritation and infections. Participant N2 described that sometimes people may have sensitivities to ostomy products and require special creams, new ostomy products and frequent health care visits, *"if we have a patient who has skin issues, allergies to the tapes, sensitivities to any other types of products, an appliance that is just not suitable to them, then we're seeing them [more often]."*

Some physicians noted that an individual's body size and shape can hinder good stoma care because people with a lot of abdominal fat are more likely to face issues with their stoma and have more complex operations.

> *You can run into problems with stomas afterwards things like you can't site them in the best position or they're flush to the skin surface, so they retract a little bit, and you know what the common denominator in almost every single time is obesity.* (P5)

Additionally, some physicians and nurses explained how stoma site marking is an important part of care and can prevent stoma complications by ensuring the placement is appropriate. One physician described how stoma site marking may not always take place, depending on the surgeon and the urgency of surgery.

> *If you don't request stoma site marking as part of the pre-admission clinic visit, then that wouldn't trigger that I don't think. […] And for emergent surgery I mean obviously it's in the middle of the night and it's you know crash bang has to happen that's different. But if we have even a couple of hours or a day which we sometimes do, I'll place a call directly to [an NSWOC] and get the patient marked if at all possible.* (P4)

5.2.2.2 Management of Ostomy Appliance. Nurses provided education on how to empty and change the ostomy appliance, provided samples of ostomy appliances and products for patients to try, and discussed strategies to prevent appliance mishaps. Participants underscored the importance of patients being able to self-manage their appliance at home with little or no assistance.

> *We tell patients that you need to know how to do this before you go home, then most times one of their first questions are "so the community nurse is coming in right she's going to do this?" […] So, we need to say no, no there is nobody, there is nobody at 3:00 a.m. when that pouch leaks and you need to take it off you have to know how to do this before you go home. Now I always ask that the community health nurse see them at least twice once they get home. Not to do it for them but to watch them change it and make sure they're comfortable.* (N2)

Participant P3 indicated that surgeons follow up with their patients in a clinic after discharge. Typically, the NSWOC is present at this clinic with them and both HCPs will work together to troubleshoot issues that patients are having with their ostomy/appliance.

> *So sometimes people come to the clinic and say they got problems with [their ostomy] and I'll just say show up to the clinic and I usually just do that, I tend to that in multidisciplinary fashion with the stoma therapy nurses. So, because a lot of these are sort of appliances that aren't sitting right and sometimes that's because they need a different appliance and sometimes it's because there's a hernia or a fold of skin in a bad place or something that I might be able to fix surgically but it tends to be [me] and the stoma nurse figuring that [out].* (P3)

Participants also explained that if a person is having frequent concerns with their ostomy, more frequent health care interactions may be needed. N2 outlined some common concerns, saying "*Anybody with major issues like if they're having issues with the appliance leaking. The wear time should be three to five days but if they're only getting one or two days then they're calling to see us sooner.*"

5.2.2.3 Management of Ostomy Output. This subtheme features concerns relating to controlling the volume and consistency of output (mainly through diet), as well as preventing output issues such as gas or blockages. Many dietitians noted that patients are most commonly concerned with which foods they are 'allowed' to eat, and which foods they should avoid, particularly during the initial six to eight weeks after surgery. People may be eager to eat certain foods or be wary about causing issues. As participant RD8 said, "*I think a lot of them probably [have] specific food that they might want to know [if they can eat]. [They ask] can they eat this, can they drink that, can they still drink pop, [etc.].*"

Participants described that another key concern is high output, particularly for those with ileostomies and those receiving medications that may affect output.

> *Usually when I see a patient with an ostomy, so before starting chemo, I talk to them, and I usually try to document [their] baseline output. How many times a day? How much is the bag filled and what is the consistency? We tell them that this is your baseline. If the volume increases by 50 percent, if it is watery and runny, and instead of emptying twice a day you are emptying it three times a day that's diarrhea [and] you have to bring it up to us and tell us that this is happening.* (P6)

Foods and medications can also cause excess gas which causes ballooning, and it may cause the appliance to come off and output may leak out. Ballooning can also interrupt sleep, cause an ostomy to appear more noticeable underneath clothes, cause noises, and can cause the person to feel embarrassed. Participant RD3 explained how gas was a frequent concern of patients, "*Gas is a big one, your patient is calling and saying that their bag is blowing up so much that it's popping off overnight while they're in bed.*"

Dietitians were also involved in addressing concerns about blockages. Participants explained that it is important to prevent blockages from occurring as they can be quite painful, may need medical intervention, and can result in surgery. Participants described that some patients were quite fearful of a blockage occurring and were very concerned about their diet and output.

> *They may have heard somewhere maybe from nursing staff or whatever prior to [seeing me] that there are foods that could cause blockages. So that's often one that I get asked specifically, like "what do I need to avoid to ensure that I don't get a blockage?"* (RD1)

A support group leader also identified that at meetings, people with ostomies may discuss which foods they avoid (out of fear of a blockage) and different beliefs around food.

> *They're afraid of nuts, and popcorn, and like seeds, and anything that fibre, they seem to be very afraid of fibre not realizing you still need fibre. [...] They think that it's [fibre] going to cause output to be too fast or give them blockages. Everyone is terrified of a blockage.* (SGL2)

Participants also described how at times, patients may become hyperaware of their diet and output, and try to manipulate their ostomy to have less output, in a way that may undermine their nutritional needs.

> *There are definitely some people that would you know they can be very, very focused on you know what they eat, and when they eat, and how that's going to impact output. And they have real concerns over "I don't want this to be happening while I'm out so I'm not going to eat before I go out" or "I'm going to eat very light the day before because I know I got things going on the next day" and so that can be an issue for people because they don't want to have to deal with their ostomy sometimes when they're out in public, or they don't want to worry about gas and things like that.* (RD5)

5.2.2.4 Nutritional Needs. Factors that can influence a patient's nutritional status include hydration, fibre, low intake, and disordered eating behaviours. For example, participant RD6 described the importance of good hydration:

> *So, a lot of times people have the misconception when they have high output to not drink more water so I usually recommend to have […] more fluids, water, weak teas, milk, fruit juices, [and] to add more potassium-rich foods so like potatoes, tomato juice, milk, [etc.], because if you're having high output, you might be at risk of dehydration.* (RD6)

Participants stated that misconceptions about hydration and confusion around types of fibre were common. Dietitians advised patients to restrict high-fibre foods in the first six to eight weeks of recovery, and they also identified the need to increase soluble fibre and decreased insoluble fibre in a patient's diet when experiencing high output.

Participant RD2 explained how in some cases, a person may have very low food intake and require intravenous Total Parenteral Nutrition (TPN) during their hospital admission. If a person's intake has become limited, they are at risk of malnutrition. Dietitians discussed the importance of monitoring and supplementing intake.

> *[Goals would include] progressing them from a TPN to oral intake and [decreasing TPN] while they're eating. And if their intake remains low while they're here, we supplement with nutritional supplements like Ensure, Boost those sorts of things maybe do some like menu marking or meal preference for them so that their intake is optimized.* (RD2)

Some dietitians discussed how patients who have difficulty adjusting to their new normal may compromise their nutritional status and/or develop disordered eating habits. For example, patients may defer meals in an effort to minimize their ostomy's activity.

> *A lot of the patients we see their ostomies more indirectly interfere with their nutrition status. It's not because they have a poorly functioning ostomy it's just the mental adjustment to this new way of life. […] I had several patients who think if they don't eat nothing has got to come out and "I don't want anything to come out especially while I'm in church," or "while I'm at work," or whatever the case*

> *is so we see a lot of people kind of restrict their intake because of that.* (RD3)

Likewise, participant RD5 highlighted that people adjust to change differently, and sometimes patients are anxious about eating because they are afraid of a blockage or other issue related to their ostomy.

> *We go from some people who just they take it with a grain of salt and they just go and do it. And then we also have some patients who have you know quite a bit of I want to say like mental anguish associated with it where they really struggle with the acceptance of how their life has changed and how their bodily function has changed and sometimes those patients do need more support and like it could be like some patients who are very anxious in that way they almost want to ask you [about] every individual food […] and so you're trying to work with them to help build their confidence to know that you can kind of, it's not all or nothing and it's about trying small amounts of things if you're not [sure], and you know letting them wade into the pool like sort of gently. But as different as people are that's how different the experiences could be.* (RD5)

5.2.2.5 Sex and Intimacy. Patients may have concerns about engaging in sexual activity when they have an ostomy and their reservations about being intimate with their partner. Participants discussed how people with ostomies experience a lot of change, and changes in physical appearance can affect body image and confidence, which in turn can affect their sexual health, romantic relationships, and their desire to seek intimacy.

> *They may not want their partner to see them. They may not want any intimacy with their partners – for younger people that's a big thing is the intimacy. And some of that you […] probably don't see while they're in hospital. It's probably once they go home that they have this issue, that they're probably in separate bedrooms and things like that right? And you may not know that for months later when they come and say "we don't have anything like that anymore because of this bag" […] and "I don't want him or her to see it or you know."* (N2)

Sex can be a challenging topic for people to openly discuss with their HCP. Patients may be more likely to discuss it at certain points in their care, or in different settings.

> *Sometimes people are, like all over wanting to talk about it [sex and intimacy] and sometimes they aren't. After surgery, generally I'll bring it up or… if I can give them the information preoperatively it might come up there. Often times post-*

> *op it's just not the time to talk about it, so it's in the handouts and they'll talk about it if they want when they come back to the post-op session. That said, they will talk about it [sex and intimacy] in the support groups. Like the people that come to the support groups are generally… they have accepted it [the ostomy], are very open about [life with an ostomy].* (N1)

Concerns about sex and intimacy may be particularly apparent depending on the patient's age and partner status, as several participants pointed out.

> *Sometimes with the younger patients they'll have issues around intimacy. Some of the older patients, not so much – they seem to be a little bit more 'go with the flow' as far as that goes. But every now and then I've had a few patients come in in their late 30s, early 40s, maybe in new relationships or maybe even single and wanting to get out and get new relationship, and it can be a big mental hang-up there as well. They feel like if they get into a position that involves some intimacy, they're a little bit reluctant to delve into that.* (RD3)

5.2.2.6 Financial Considerations. Several HCPs mentioned that the cost of ostomy supplies was astronomical for some patients and that current programs and subsidies in place do not support all people who could benefit from financial support. Nurses and support group leaders were particularly concerned about this issue. Nurses described each of the current methods of payment and programs that exist and the issues that patients face when trying to obtain supplies:

> *You have to go to the pharmacy and pick it up because a lot of people think MCP covers [it, but] no it's not covered. You have to pay for this, […] [The] patient pays upfront, sends in their receipts and the money will be sent back to them from the insurance company. That can be pretty costly upfront cost for patients. They don't realize [the cost] until they [first buy them] […]. Patients who are 65 years of age and older have the Newfoundland and Labrador Prescription Drug Program card will be covered 75% for the cost of their supplies and they as well will have to pay upfront and send in their receipt. Patients who are under the umbrella of the social services program they're 100% covered and their supplies are [covered]. I [write] the list of supplies that they need, I would send it off to the special assistance program, supplies get delivered to their door, so they don't get a prescription, they don't go to a pharmacy or anything. Then we have the people who don't have any of that and they have to pay [fully] out of pocket. So, they could be people with money, or they could be people who are just at that midline where they don't have any insurance, but they also don't qualify for social*

> *assistance.* (N2)

A physician pointed out that patients with ostomies often have other elements of their disease that are causing concern and adding stress to patients' daily lives, and the affordability of supplies is an unnecessary stressor:

> *They are going through so many other things and if these guys have to worry about five or ten dollars every day for these ostomy supplies, that's one thing [they should not have to worry about].* (P6)

Participant N3 also pointed out that when a patient cannot afford supplies, it impacts the health of their stoma and their health care needs:

> *You got people who can't afford to change them [ostomy appliances] when they do leak so they're leaving them there longer than they should be and then their skin is getting burned for that reason – the [acidic] stool leaks onto the skin and burns it basically.* (N3)

Support group leaders highlighted that the affordability of supplies is a frequent concern of people with ostomies, and support groups have spent time advocating for change and have also spent time informing people with ostomies of the disability tax credit that they may be eligible for, as a means to relieve the financial stress they face.

> *We are putting a real blitz on the disability tax credit because a lot of them [people with ostomies] don't realize that they're eligible for it and right now the only people who are allowed to approve it for us are our doctors*. […] *costs of appliances are not cheap. [If a person is] having a good month changing once a week which is very rare, [they're] paying $300.00 a month. [Some are lucky they have] insurance and there's some people that just fall in between that insurance and the government just don't seem to want to listen.* (SGL3)

5.2.2.7 Lifestyle. Patients may also worry that an ostomy will prevent them from continuing their life routines and pursuing their interests. For example, participants described that patients are often worried that an ostomy will hinder their ability to be independent, participate in physical activity and sports, travel, or participate in social activities. Participant P1 commented on how they get to know the individual and how a person's lifestyle may impact the type of surgery they have:

> *We always sort of try to get an idea of what the person's life was like before they came to the hospital in terms of, are they an inactive person? Are they a marathon runner? […] Do they live alone so they need to be able to be completely independent? Do they take care of five kids so they're going to be running around and don't have time to have their stoma bag bursting open and things like that? So the discussion we usually have is what's your baseline and what's the baseline you want to get back to and that will guide a lot of [the plan] because one of the big questions for patients depending on the scenario is "when can I have this reversed?"* (P1)

Another physician, P7, explained how they considered lifestyle factors when assessing disease status and choosing a course of treatment: "*from a lifestyle standpoint, I would think: is this person able to get back to work or school? Or [attend] functions with their family that they want to be able to do?* (P7)

Similarly, nurses also discussed incorporating patients' goals into care by learning about a patient's lifestyle and supporting them to maintain that lifestyle with an ostomy. Determining the best ostomy supplies for each individual and their lifestyle was consistently mentioned as a key component of nursing care.

> *It depends what their goals are […] some of them are big into sports so like how do we protect the ostomy? […] what's your lifestyle like? We do talk about [how] having an ostomy is not intended to slow down your current lifestyle or whatever so we try to adjust looking at pouching, different pouching options*. (N1)

> *With regards to swimming and things like that, there's all kinds of different products that we can use. So basically, you just try to match them up with whatever it is they need to establish what they need in their life. So, if someone is concerned about swimming there's certain pouches that we can offer to them and set them up with those.* (N3)

Participant P1 gave an example of when the goals of surgical therapy and considerations of lifestyle are unique. In the case of palliative care, a stoma may be created to prevent pain and improve quality of life (QOL):

> *So sometimes a stoma is provided as a palliative procedure that hasn't necessarily cured their cancer and so their goal of care would be very different from someone else. Oftentimes, it's provided for the purpose of keeping them comfortable so they can have a few more months of life without pain or in a way that they can get home and not be in hospital for the rest of [their life].* (P1)

5.2.2.8 Coping and Mental Health. People with ostomies must cope with changes and adjust to a new state of normal, which can affect their mental health and well-being. Many participants commented on examples of when patients coped poorly with the changes caused by having an ostomy.

> *I know that a lot of people struggle with living with an ostomy. I've seen people not leave their houses once they get [an ostomy] because it's detrimental to them, like they can't imagine going out in society with this bag on their side.* (N3)

Several participants commented that in some cases patients may present with medical complaints that relate to physical health, but in reality, they are facing psychosocial issues that are less overt.

> *For some of them I guess the whole ostomy and stoma and appliance can be quite a psychological barrier you know, there's lots of issues that come up in that regard. Some patients do quite well with it and some patients – they come back with a lot of medical-type complaints but oftentimes, I think the underlying issue is a more psychological one as opposed to a Crohn's disease, or you know an ostomy-related issue. Some patients are quite, quite traumatized when they wake up with one right? Because some of them end up with one and they never anticipate that they're going to have one, and then you know I see patients in my clinic who look at while I'm examining them, and you can see the disgust in their face when they look at their abdomen.* (P7)

Additionally, Participant P7 believed that a patient's diagnosis, age, and/or gender may impact a person's ability to adjust to their ostomy. For example, a person with long-term gastrointestinal complaints may adapt more easily than someone with a sudden cancer diagnosis. The physician went on to describe and contrast two patients, one who coped well, and one who struggled with accepting their new normal.

> *I'll give you an example of a patient I had, and he was in construction and [had] really bad ulcerative colitis for years. And I was trying to convince him to get surgery done and when he got it done, he [says] "this is wonderful doctor I can go out and play golf now, and you know I'll just empty appliance before I go out on the golf course, [...] I can go back to social situations." And he thought it was friggin' fantastic. But then I got a young [patient] who was in her late 30s and she ended up getting rectal cancer because of her Crohn's disease and it's been a psychological nightmare for her trying to deal with it because she thought her Crohn's was under control, which it was, but then cancer crept into the picture. So, she really didn't have any choice and you know it's been a few years now and she can't accept it [...] so maybe gender [affects experience], the age you get [an ostomy] definitely has an impact.* (P7)

While many saw their HCP role as one concerned with the *physical* needs of patients with ostomies, several participants explained that a patient's *psychosocial* needs can be a bigger issue.

> *It's a big life-changer for people. Like no one wakes up in the morning and says, "oh I'd like to have an ostomy bag." It's not something anybody would want to have happened to them and it does take some people a lot longer than others just to accept their new normal and come to terms with life. I think it's a bigger psychological adjustment than it is a physical adjustment.* (N1)

Some participants described that in some cases, a patient may really struggle with coming to terms with having an ostomy, choose not to manage it on their own, and rely on their caregiver or partner. Participant N2 described how this may appear:

> *Not wanting to look at the stoma. Not wanting to change the appliance. Not wanting to empty the appliance. Crying when you see them – and I got that effect on people, I walk in the room and they look at me it's like "oh my God she's here" and they may, if they're really not coping, they may start to cry.* (N2)

Participant N2 went on to explain how unacceptance may result in a person limiting their socialization and routine day-to-day activities that they perceive as no longer possible due to their ostomy and their fear of embarrassment.

> *Some will have trouble going to a restaurant or going to a movie or going to*

> *church even because if they have gas, it's gas the same as if you were having gas the regular way it makes a noise. [...] When it comes to going to restaurants and dining out it's the "how active is my ostomy going to be while I'm out there?" like "am I going to have a leak in a public place?" So even that type of stuff is really bothersome for people and one thing I always say to them, "look, whenever you go anywhere just be sure you have an extra appliance with you, an extra pouch, make sure you have something you can clean yourself with, make sure you have you know all the things you need if you do have an accident that you can go right into a washroom and you know take it off and clean it up and put new on."* (N2)

HCPs tried to address psychosocial concerns by referring to mental health resources available (which appeared easier to access while a person is admitted to a hospital), or by mentioning support groups. But not all patients availed of such services.

> *A small percentage [of patients with ostomies] really don't cope well, and you can get that while they're in hospital. I often ask the physician if they can refer them to psychology and get them seen before they are discharged from hospital to help. Some will avail of it. I had a patient recently who I really thought needed it and she – they came by twice and she refused to see them.* (N2)

Several participants explained how they try to support patients within their own practice.

> *Lots of times we are their support as well because patients will call us, and say they're not coping well, so we'll try and support them the best we can. Sometimes that involves a visit and [...] we'll go through everything again and then [say] "I can answer some more of your questions" and "I have patients who have done that as well" and [...] I think they do okay when they come because [they say] "thank you for seeing me, you've helped a lot."* (N2)

The role that a dietitian played in supporting a patient from the perspective of psychosocial adjustment varied; some saw it as part of their responsibility to help the person cope emotionally, and others viewed it as external to their role as a dietitian, as seen in the following excerpts:

> *I guess the biggest thing is as healthcare professionals, it's important to remember that this isn't just like a small thing for them, like their whole lives essentially have changed. So just being there and helping them through that process, because your support and your knowledge can go a long way with helping them overcome and reach that normalcy again in their life, and to just overall achieve a good quality of life with the [ostomy].* (RD6)

> *It's [psychosocial discussion] not something that I actually initiate but it is something that the patient is upset about, and it does happen. You go in and right away they're tearful they don't want to look at it. Because I always ask if it's started to function, if there's any stool or gas or liquid or anything in there before I start my session, and sometimes that might trigger a little bit of a reaction. And if the patient is upset with it, I will certainly just offer support and comfort, but it isn't certainly anything I start with it's not part of my role. […] It's a big change for their appearance, it's a big change in learning how to do something new, and [I] just offer support [and say] that there are lots of people here to help you deal with this and if you do need to speak to somebody there are people around […] but it's not a regular thing for me to have this conversation with a patient.* (RD2)

When asked how they support people during psychosocial adaption to having an ostomy, physicians had varying responses and perspectives. One physician described how they use positive language to encourage the patient and to help them understand that an ostomy is a better alternative compared to other possibilities given their disease state:

> *It's difficult. It's a really difficult conversation and I find that different patients respond to different types of counselling better. One thing I try to say to people is sort of people are always comparing their current state to their previous state and I think one thing I try to explain to people is that that state isn't there anymore. Unfortunately, this is what your body has done, and these are options. I think that trying to compare yourself to or always getting back to the way you were before is not really a good way to look at it because it's just not an option that's on the table anymore and these are the options that are ahead of us […] I try to frame it in a positive way, and we are always – we always try to them like we're very happy with the outcome of this. The stoma is working really well and even though it comes out of a different place on your body it's – your [gastrointestinal] tract is working great now, […]. We find that if everyone on the team is telling them like this is, we're very happy with this outcome sometimes that kind of frames it for them that compared to the alternative this is a really good outcome.* (P1)

Another physician stated that they do not address psychosocial issues, and that support is not part of the care that they provide:

> *I will admit to doing almost nothing about that. Yeah, I don't know, I mean maybe there is resources, maybe there isn't – I honestly have no idea and I suspect if there are, a lot of the stoma nurses might [know]. I know there's like support groups and there's stoma associations and I even talked to one of those groups once did a mini lecture. So, these exist whether that's what the patient is looking for I don't know but I honestly don't formally address psychosocial issues.* (P3)

In contrast, support group leaders highlighted various interactions they have had with people with ostomies. One leader shared an example of a member who had not come to terms with having an ostomy and did not manage their ostomy on their own:

> *We do have a few women who have never changed their ostomy and they have an ostomy. [One person has had one] for about five years and her husband changes hers all the time. And I look at her and say you know, "what are you going to do if something happens to your husband? You're there and you don't know nothing about it. You got to learn." [They say] "No he's there he'll do it." Okay. So, these are the little things you got to get across to the clients – that you can't let somebody else do all the work and that it's not a disgrace, it's like [treating] cancer. If you have cancer, you go get chemo, you go get radiation, so you're doing something. [...] [When] you get an ostomy that saves your life and some of them just don't realize that.* (SGL3)

Another leader commented on how their meetings create a space for people to share their experiences and for people to listen and learn from others:

> *We have some meetings where they can share, they share. It depends on the person. Some members say, "I don't mind, I can express myself to you, and my experiences, I don't mind at all to share what I [have] gone through with it" [...] It depends on your personality if you are a [talkative] person or not or just absorb everything really right. So, you have to respect that too.* (SGL1)

One support group leader commented on gender differences that they have observed throughout their involvement in the support group:

> *Women are easier to deal with than men because men, ah not all of [them] but a lot of them, get self-pity. Then after they come [...] and they start talking to them [other members] and they start to realize, "I'm not the only one here" and they start talking about what's going to happen [because of their ostomy] and they're talking among them like as a group, as a group of men, so they start to break down that wall that was there and it works, it really does work.* (SGL3)

Support group leaders explained that, ultimately, the goal of support groups is to help people mentally adapt to having an ostomy. Leaders stated that they encourage members to not let their ostomy hold them back from doing what they want to do and living the way they want to live.

> *By talking to them and just trying to explain to them, "you're not your ostomy you know, your ostomy is you and you have to deal with it." [...] we had a member who thought she couldn't swim anymore, and we just stopped and said, "why can't you swim," [and she said] "because I have an ostomy." Go on b'y get in the pool there's no reason why you can's swim. There's people climbing mountains and I mean professional mountain climbers with ostomies. [...] there should be nothing that you did before that you can't do after with an ostomy and a lot of people don't realize it.* (SGL3)

5.2.3 Team Functioning

HCPs described how they worked together to provide patient care in various health care settings, and barriers that impede team functioning. This theme has two subthemes: Communications and Interactions, and Barriers to Care.

5.2.3.1 Communication and Interactions. HCPs explained that they communicate with one another to coordinate care in a variety of ways, including referral processes, phone calls, and face-to-face meetings (i.e., rounds). For some, face-to-face communication with other HCPs was easy because they work in close proximity to one another.

> *We typically don't get very much involved with [the ostomy appliance] itself, however, the ostomy nurses are right in my department [...], so we have pretty close proximity to them, and we frequently set up appointments for our patients to get in and see the ostomy nurses while they're visiting us as well. Worst case scenario we provide the contact information for the ostomy nurses, and they'll usually answer any of the questions about ostomy care with regards to devices and the actual ostomy care.* (RD3)

In contrast, other participants referred to HCPs at a different site and may never interact face-to-face.

> *Well so we just fill out the form, the request to see a dietitian and the form gets faxed over. The dietitian sees them, and we'll get a letter back, that's about it. [...] the dietitians used to be here at [the hospital] with us or we used to have one and then at least we'd see her or him and be able to interact. I mean the cancer centre has got them onsite over there. It would be nice if we had one and you know actually, we could use [dietitians] in our patient clinics, but that resource*

> *doesn't exist so it's just like fax off the note and then you get a note back. […] So, it's very impersonal and no real follow-up.* (P7)

Participants described how they may write letters to others who are involved in the patient's care and charting itself is a frequently used communication tool to ensure all HCPs have access to relevant information.

> *So, we have standard guidelines that we send family doctors a letter and send a copy of that letter to the patient as well. So, both of them know exactly [what the plan is] and that is mentioned in our notes as well and we keep track of all those things so that both of them know what needs to be done when it needs to be done and if something is not happening, they get back to us.* (P6)

Some participants used charting tools to connect with other HCPs and bring their attention to specific needs or issues.

> *There's a thing in [the patient's chart] called reminders and so if I need to speak to a physician the best way to contact them is to send them a reminder on the patient's chart. And so that's where if I had concerns about someone or I thought they should get blood work done or something like that, I would send the reminder on the chart for the physician because that's usually the best way to get them. And if it's urgent you can mark it as urgent or something like that.* (RD5)

Many participants who care for patients in a hospital setting mentioned that their site/unit holds in-person rounds, or that they used to before the COVID-19 pandemic. During rounds, HCPs discuss each patient in their care, and this can often trigger a referral for a dietitian or another professional, based on the patient's needs.

> *So, we have daily rounds every day on every patient. So, it's multidisciplinary, we'd have all of the allied health team which would be the physio, occupational therapist, dietitian, you'd have the charge nurse, the patient's nurse, the social worker, […] so every patient is discussed every day. So, anything that anyone learned about any particular patient that day would be shared in rounds and brought to the attention of whoever needed to be involved.* (RD2)

Participant RD1 described how members of the health care team work together to meet the patient's needs by having quick communication between professions to pass on any relevant pieces of information:

> *So, I always say to the patient on my visit now if you think of anything else let your nurse know, or if anyone else on the healthcare team is in having a chat and you think about something let them know and I can pop back with some information or just pop in and answer your questions. So hopefully there's lots of routes for patients to ask questions and they don't have to feel that there's definitive lines between us [so] you can ask one person and they'll bring it back to me, and the same if they have questions about how am I going to homecare or whatever. Well, I can take that back and ask the social worker to follow-up with a visit. So hopefully that continuum of healthcare is very fluid here.* (RD1)

Participant RD1 also pointed out the benefits of having a good rapport with other HCPs, and how they worked closely with community health to ensure a patient received follow-up dietetic counselling as needed.

> *I have a good connection with a number of them [community health nurses] too so if they go into the home and they realize okay there seems like there's some questions surrounding nutrition here and whatnot they'll either email me or they'll telephone me, and they'll build that bridge between me and the client. [...] I think it's so important to build those relationships, especially with community health, because again, they are the people who are going to be going into the home after that person is discharged from hospital. And as we all know the situation at home is not the same as what it is in hospital because you're on your own in a sense. [...] So I think it's so important to build those relationships with your community partners [...] and with physicians too because those patients may be going back for follow-up, [...] and so again that comfort level of just picking up the phone and saying "listen so and so was here today and they have some questions that I couldn't answer, could you, would you mind just giving them a shout or bringing them back for some follow-up?" or whatever.* (RD1)

5.2.3.1.1 Liaising with Support Groups. Some HCPs were very knowledgeable and sometimes even involved in ostomy support groups.

> *We started our own support group, so we meet once a month for a couple hours. I get a free room at the hospital, and it would get advertised through Lawton's and on cable and on the radio and things like that and I put it up on the board outside clinic and whoever who would want to [can] come.* (N1)

However, the COVID-19 pandemic has disrupted many of the relationships between HCPs and support groups. During the time of the interviews, no groups were meeting in person.

> *So, then we tried to get it started again and then COVID kind of threw us a curveball so now it's at a stand still again, but we are trying to get that group re-established here. […] which is sad because even I can tell you like the few meetings that we did have were like a breath of fresh air to sit in the room with people living with ostomies and just hear them share their stories, talk about issues they would have, and give each other tips on things they can do. And then even hearing people link up like making friends basically so that they can get together outside this group and sit down have a chat about their experiences with their ostomies. And the support piece is huge for these people.* (N3)

Some HCPs were less involved in support groups but regularly discussed groups as an available resource for patients.

> *I would give them that [Ostomy Canada] pamphlet when they leave the hospital […] I don't often attend their meetings. We're able to of course I mean I do pay the $25.00 a year just to support them and I have attended some meetings and I have attended some of their social events. […] I tell them even if you don't want to attend the meetings you do, for the $25.00 you do get access to a magazine and a local newsletter [with information about living with an ostomy]. […] So [they get some information] even if they don't want to attend [groups].* (N2)

Others only talked about support groups with patients in specific scenarios when they thought someone may benefit, as opposed to routinely in their care.

> *Yup, no I know there's groups out there and you know if, sometimes I mention that to patients and then I would, I'd have to go to the internet to find out the exact contact, but I do know that there are groups out there and some of my patients are involved.* (P7)

Some HCPs had participated in the support groups as guest speakers but otherwise, they were not involved in the group or in referring patients.

> *We have been involved in some ostomy support groups over the years. It's not a regular part of our work but we've all kind of spoken at support groups over the years from time to time. Other than that, not a whole lot of formal involvement.* (RD3)

Some HCPs were either not aware of the support groups at all, or had very little knowledge of what groups are available to patients with ostomies or how they operated, as seen in the following excerpts:

> *No, I actually, that's probably something it would be good to know because I really only heard about it sort of second-hand you know by patients saying "oh, I'm involved with this support group" you know but I feel like I don't know enough about it to be the one referring them to it.* (RD5)
>
> *So, I know that there are particular [groups] for colon cancers because I've been invited to one or two to just do some quick lectures and discussions but I'm not sure that they are specific for ostomies or in general for colon cancers.* (P6)

Commonly, participants stated that did not refer individuals to the support groups, and said that usually, NSWOCs would communicate any information about the resources available.

> *I don't refer them myself, but I think those who have been involved with it… they either seek it out themselves or somewhere along the line [it gets] mentioned to them that it's something that they might wish to consider.* (P5)

Some participants did say they would like to learn more about what groups are available and be able to communicate that information to patients.

> *I haven't [been involved]. I haven't and I don't actually know, sorry I don't have a good idea of what other physicians or surgeons in my community have involvement with that. […] I would like to know, like I think that would be something helpful for us to know about, because like I said oftentimes people are coming into our clinics and we don't know exactly what to offer them. Structurally the stoma looks great and it's working great and that's kind of where our brains are focused on. So, I think the more groups and stuff that we had access to, and even just having some of those pamphlets in our clinics would be really helpful and like I said maybe some of the surgeons are already very aware of it, but I think more involvement from our end would be helpful.* (P1)

5.2.3.2 Barriers to Care. Participants discussed several factors that are necessary for good patient care and disclosed several issues that they face that prevent or impede the provision of optimal patient care to all patients. These barriers to care range in terms of their level of impact on patient care, the complexity of the issue, and the sort of resources that would be needed to create change.

5.2.3.2.1 Limited Follow-Up. The majority of resources available to provide patient education for people with ostomies are focused on providing care in the days immediately after surgery. For example, a nurse discussed the need to improve outpatient support available to ensure that patients cope well with the changes they have experienced.

> *While patients are in hospital, I think they get a fair bit of care and support because the whole team is there, everybody is there if they needed anybody, you know if they needed three ostomy sessions, they got it. If they need five ostomy sessions, they usually get it. Once discharged that's I think where there is a lack [of support]. [...] if they [patients] say "I'm not doing well," the nurse may go back or you have patients who are really shy about it – they might see the nurse one or two times and say, "okay I'm alright," but not really be alright. [...] it's just more support [is needed] and I don't even know how we could do that. I mean we have a support group [...] but if you're not a member of this group you're probably, you're not getting that part of it right.* (N2)

NSWOCs were repeatedly viewed as a critical resource for good patient care, but limited resources may contribute to a lack of follow-up care. According to participants, there are seven NSWOCs located in NL, and they provide inpatient and outpatient care to a large volume of patients. Participant N1 believed more NSWOCs were needed in NL: "*You know [NSWOCs are] a limited resource [...] I'd like to have another NSWOC but it's just not in the budget."* It was common for participants to comment on how busy NSWOCs were, and how patient care was affected by a limited number of NSWOCs (e.g., patients may have a prolonged hospital admission while they wait to see an NSWOC). The Central region has one NSWOC who is designated for community care, whereas all other nurses are based in the hospital. This may cause regional differences in the frequency of follow-up care provided.

> *Central Health is the only place that has a community nurse [who is an NSWOC] now she can't [get everywhere] herself because it's a very large geographical*

> *area but they, you know they have that ability [to travel]. […] It would be nice if there was a nurse who, an [NSWOC] who could make follow-up home visits within the first month that they're discharged from hospital [in any region]. […] it would be nice to have [an NSWOC] in the community [so] that they wouldn't have to come [into a hospital] when they're right after having surgery.* (N2)

Participants also frequently discussed concerns around referral processes for patients being discharged from the hospital. Some participants noted that they have been positive changes made to the referral process, but issues remain for many such as missed or late referrals, complex referral processes, or a lack of standardized care. Most HCPs said that there was a general understanding that all patients would receive a dietitian referral after ostomy surgery for inpatient services. However, it is unclear if this happens across the province, or if access to dietetic services is sufficient in all areas.

> *We do have people that come out [of hospital] and feel like they weren't prepared well enough for [their ostomy], but I think those are cases where they think they are when they're in [hospital] and they're anxious to get home. And when they get home, they just forget what they were taught, and they can't do it as they could when they were in the hospital. I think every person with an ostomy should be referred to a dietitian and see a dietitian for at least a conversation before they leave the hospital. I don't think that happens. Maybe if they want to see and ask to see they do but then a lot of times it's because the dietitian just has time constraints and can't get around to see all those people before they are actually discharged from the hospital.* (N3)

This quote also highlights the importance of outpatient follow-up in addition to care received in the hospital – information may be forgotten, and needs may change once a person has returned home. Meanwhile, some dietitians pointed out that many patients with ostomies are not referred to outpatient dietitians after surgery, as participant RD6 said, "*I guess the biggest obstacles would be in outpatients, if you don't get the referral for somebody who is having issues with ostomies you won't be able to help them.*"

Discussion about the availability of outpatient dietitians and referral processes was inconsistent. With the exception of cancer care, it is unclear when, why, or how a patient may see a dietitian after discharge from the hospital. If a patient is receiving further treatment at the cancer care clinic (i.e., chemotherapy or radiation) after surgery, it is likely they will be followed by a dietitian. Otherwise, follow-up varies greatly.

> *The outpatient dietitian support strikes me as variable. In hospital, it's certainly very good. My ability to get an outpatient dietitian assessment [varies], not specifically for people with stoma and nutritional issues, but for anybody. I'm uncertain as to the factors involved there, but it doesn't seem like necessarily it happens in a timely fashion. [...] it takes a long time for outpatients to get seen by a dietitian. [...] That [paperwork] can sometimes be a little bit of impediment and it might be the reason why people are not seen.* (P2)

Additionally, participant N3 noted that it would be beneficial to have a dietitian with specific training related to ostomies who could become a go-to resource for patients: "*To have a dietitian who focuses solely on ostomy patients so that they would always be available to them while they're in hospital, before they're discharged, or even after discharge, that would be a great thing.*"

5.2.3.2.2 Lack of Interdisciplinary Care Settings. Participants' discussed limitations of the current model of care, specifically due to a lack of support for working in an interdisciplinary team setting, as explained by participant P7:

> *It's really quite sad actually, you know I've been working for years to try to get a nurse practitioner to help us out in our IBD clinics and there isn't [a nurse practioner]. [The regional health authority] hasn't decided they want to pursue that yet. You know our dietitian – we don't have a specific dietitian so oftentimes our patients end up getting lumped in with the dietitians who are doing diabetes education. [...] and here unfortunately where we're kind of, like all the physicians are kind of like solo, separated from each other.* (P7)

Another physician, who was early in their career, also pointed out that they had a lack of understanding of the various roles of HCPs throughout their education and practice.

> *Yeah, it's a pretty surface-level understanding of the care they're [patients]*

> *getting from other professionals from my end which is definitely my own fault. But I think the way the system is designed, that most of us go through without actually learning a whole lot about that which is definitely a flaw in the system, and it's especially difficult because we're often the gatekeepers. We're the ones that are scheduling [patients] to see them [other HCPs] post-operatively and all these other people can't help them if we don't connect them with them.* (P1)

Participants had several ideas of how care could be provided to patients. Often these ideas stemmed from previous experiences in another location.

> *So I mean [when I left another province] years ago, they were further ahead there then than we are now. There would be multidisciplinary clinics so the clinics would often have a gastroenterologist and a colorectal surgeon side by side. So the surgeons clinic would run, and he'd see whatever he needed to see, and the [gatroenterologist] would see whatever they needed to see, and then if they needed to actually liaise, they were in the clinic together so they could. There was a dietitian present in clinic. Clinics would have a nurse practitioner present who would follow these more chronic patients along. [...] some clinics now in Alberta would have access to a pharmacist on-site and everything.* (P7)

Participant P1 compared health care that is provided to ostomy patients to care provided in orthopedics:

> *I think that it would be cool if we could coordinate [care] so that patients had one time to come in – kind of like [on] follow-up cast day [in orthopedics]. So there's an occupational therapist in the clinic and all the patients that are coming are for that so they can just see both people at once. I guess if we could improve the system that would be cool if we could coordinate all the patients that are getting follow-up and the stoma nurse could be there.* (P1)

Additionally, some participants discussed the need to improve interdisciplinary care to have expertise available to address specific patient concerns such as sleep deprivation, as well as sexual health.

> *We are trying to get somebody for sleep as well. These people are on different medications and mental stress and all that so a combination of those things like mental health and sleep deprivation or poor sleep or whatever and sexual health so all those [resources are needed].* (P6)

5.2.3.2.3 Geography. Participants expressed concerns about how the sparse population and the high number of rural communities of NL impede the availability of consistent, good care, and produced gaps in services. Physicians voiced concerns that little was known about how patients received care in rural areas, and that perhaps care received at different centres varied.

> *So I think distance is an issue because we’re a tertiary care centre and we see lots of people locally. I am personally kind of unaware as to the extent of the support that they get outside of St. John’s. […] So there may be gaps in terms of support services that exist outside of St. John’s per se, and you know there’s lots of patients that I have operated on [who are not] geographically located in town, just by again to the tertiary care nature of the place I work and so people come from all over. So that’s something I’m unaware of but I suspect that it may be variable and it may well be that they don’t have the same support elsewhere.* (P2)

Another participant made a similar comment about not knowing what support is available to patients in rural areas, and whether patients had sufficient access to HCPs with adequate knowledge about stomas.

> *So for my patients in St. John’s, I think they can really good support from our [NSWOCs] […]. When patients are outside of that St. John’s catchment area, they can get a bit lost in the wind and if they’re lucky enough to have community health support with somebody who’s got a lot of knowledge about stomas then that’s great, but they may also be somewhere people are not as experienced and that can be harder for them then to access the care that they need.* (P4)

5.2.3.2.4 Mental Health Resources. Participants’ were concerned about the lack of mental health resources available for people learning to adjust to an ostomy. Several participants pointed out that the province has a lack of available resources, which prevents patients from receiving care from providers with expertise in mental health. Participants referred patients to multiple different resources including social workers, mental health nurses, counsellors, psychologists, and psychiatrists. The provider’s choice of referral appeared to depend on how easily and quickly a patient could receive access and the cost of the service.

> *Some of them [people with ostomies] I think have deeply rooted psychological issues which again I'm not trained to deal with or maybe even diagnose. I can't diagnose but you can just look at these people and some of them, some of them really struggle and there's not a lot of support for them which is unfortunate.* […] *We'll talk to them about it and get them to talk to their family doctor. And some of them [patients who have] IBD, a lot of patients [have] depression and anxiety that's not well diagnosed either. So you know I'll often ask the family doctor to re-evaluate them in that regard and in some really bad situations I've had patients seen by psychiatrists but you know it's awfully hard to see a [psychiatrist] here in Newfoundland but on occasion, I've had to do that, and then occasionally I'll try to make a referral to psychology. Again the downside to psychology [is that] the patients often need to pay for it themselves and it's not well funded through Eastern Health or MCP.* (P7)

Participants frequently cited the need for more mental health resources and some stated that they would ideally like to see dedicated resources that would be easily accessible and familiar with the needs of ostomy patients. One physician (P7) stated, "*We could easily have one psychologist employed full-time in [each large hospital] just dealing with GI and surgery-related psychological issues.*" A nurse (N3) shared a similar sentiment: "*The counselling, I mean it would be lovely to have someone – staff at each health authority who could counsel these people as needed. I think that would go a long way*." Participant P6 stated that the referral process to see certain specialists is a complex process and that often HCPs may avoid putting in a referral because they know the waitlist is too long given the patient's needs, and they may look at alternative ways they can help the patient. The physician described how this may cause a further issue because the evidence of demand for that specialty may not represent the true demand.

> *I think access to mental health professionals should be easier and those people should be available easier rather than a complex process. A lot of places have kind of learned a sense of helplessness that [it] is going to take so long to get certain specialists to see a patient that what's the benefit of putting in the consult […] when it's going to take months for somebody to see a patient.* (P6)

Nurses discussed the programs offered by ostomy supply companies and their mental health support. Oftentimes, patients were enrolled in these programs with the help of nurses and therefore, they had access to a variety of virtual supports. These programs help offset the lack of resources available through the public health system.

> *Unfortunately, we don't have a lot of support when it comes to that [mental health] and that is a huge thing, I mean learning to live with an ostomy, I can't imagine what these people go through and how difficult it is. Luckily, the ostomy companies Hollister, Coloplast, ConvaTec […], they have support groups that these people can call for counselling and they are linked up with these companies before they're discharged from the hospital as well. I mean we try to provide as much emotional support as we can and certainly talk to them about anything they want to talk about and provide that kind of emotional support but in my opinion, you know it's limited, like it would be nice to have a counsellor who focuses solely on ostomy care for like people living with ostomies and someone who's an expert on counselling people and [help] with these issues because I know that a lot of people struggle with living with an ostomy.* (N3)

Some providers believed that a lack of available mental health counselling for people with ostomies made it difficult to provide other care, such as dietetic counselling. Many dietitians agreed that the patient's adjustment to life with an ostomy impacted the patient's ability to engage in health care and manage their condition.

> *The other barrier is also to do with the patient, the psychosocial piece of the patient care. In fact in the regard that for some patients who are having really difficult time adjusting. […] I think they haven't adjusted to the fact that they have the ostomy. So sometimes that impedes them from actually seeking the help and accepting the help that we might be able to provide. […] I've had a couple of patients over the years who physically didn't deal with the ostomy at all, they had their spouse or caregiver do all of it. And so to try to speak with that patient and give them help and give them advice and help them it can be really, really hard because they don't want to talk about it all they're completely shut down about it..* (RD5)

Dietitians often discussed a lack of mental health counselling and how counselling may help patients' mental health and increase the effectiveness of dietetic counselling.

> *So I just feel like there could be a lot better upfront counselling I'm not sure who*

> *would provide that even if it was a psychologist or someone like that because there are a lot of lifestyle and emotional things that change with ostomy surgery and I don't feel like my patients come to me well equipped to deal with them.* (RD3)

5.2.4 The Dietitian

Dietitians described their preparedness to holistically support people with ostomies, and the availability of dietetic resources and decision-making support during dietetic counselling. The Dietitian has two subthemes: Training, and Sources of Information.

5.2.4.1 Training. In this study, dietitians stated that they did not feel equipped or trained to handle psychosocial components of care, and many stated that psychosocial support was not a part of their role. Participants agreed it is challenging to support people who are having difficulty coming to terms with their ostomy. For example, participant RD3 commented that they felt that dietitians were not trained to know how to support a patient's mental and emotional health when they are having a challenging time adjusting to having an ostomy.

> *We're not necessarily trained in that type of counselling but also, it's hard to change the way a person feels, and obviously when it's impacting on their nutrition status that's what kind of brings us into the picture, but oftentimes it doesn't have anything necessarily to do with food. It's almost similar to like eating disorders in some ways, it's not necessarily about the food – it's about the emotional and mental notions regarding the ostomy […] personally, I find it's quite challenging to try to convince people that it's okay for [their] ostomy to work […]. I've had a lot of patients who have gotten themselves in some pretty bad positions because they're at their happiest when nothing is coming out of their ostomy and the next thing you know they've got a bowel obstruction because they've gotten so blocked up and it's like how do you convince somebody that that's not a good situation to be in. So I often feel like we could probably use more training in that psychosocial aspect because most of it like I said, it comes from just experience with those patients over the years and I guess you have to wonder sometimes if you're being as effective as you could be.* (RD3)

Moreover, dietitians had different perspectives on the goals of dietetic counselling. Sometimes goals were patient-centred, other times they were dictated by the dietitian (usually with a biomedical focus), and sometimes the goals were unclear. For example, when asked how they incorporate a patient's goals into care, one dietitian stated *"I don't typically, I suppose, well I suppose I should be, but I don't typically teach that way. Theoretically, maybe we should be, but I don't usually ask them what their nutritional goals are."* In contrast, RD8 discussed the importance of recognizing that people have complex lives and experiences, everyone has a different ability to cope with changes in their life, and goals may be different for different people:

> *I think just to kind of keep in mind that it's more than just kind of going into someone's room and revealing a diet and kind of assuming that everything is good. There's probably a lot more [going on], like I said a lot of these people have [a] cancer diagnosis and other underlying health issues that they're trying to deal with on top of this. Some people do very well with it and it really improves their quality of life because maybe they suffered from some kind of bowel [disease] for a long time and the ostomy is a good thing for them, and they probably do well from a mental health perspective I guess, and they probably have the supports they need at home. Not everybody has [support] and so it's just good to kind of remind yourself about those things.* (RD8)

Building on this idea, participant RD1 commented that part of their role as a dietitian is learning where the patient stands in terms of their recovery and adaptation to change, supporting the patient by providing them with the information and support they need at that moment, and building goals together.

> *I think [incorporating the patient's goal into care] starts from day one when I go in there and just kind of figure out with them where they are with this. Some of them are as you know like they weren't prepared for this at all, so they don't even have their mind around all of this they're just in survival mode. All they want is kind of the basics to get them through like "what can I eat" and "what should I stay away from." Others are going to be more curious and want to know a wide spectrum of things. So for me, it's kind of just feeling out where the patient is at [in] that particular moment, and building those goals around that moment in time,*

> *and working on that as they kind of move forward from [surgery].* (RD1)

Some participants commented on goals that the patients make individually, and the goals that HCPs have for them. For instance, participant RD3 discussed how at times, a patient may make a personal goal that is harmful and causes a need for negotiation and behaviour modification. This quote highlights the discrepancy that can occur between an HCP's recommendation and a patient's goal:

> *Well, you obviously don't want to lose sight of the [patient's goals] because they're going to be the kind of directing where they want things to go. I guess sometimes it could be contentious issues if somebody comes in and they're quite firm on that they don't want to eat from 8-5 because they have to work and they don't want their ostomy to do anything. We spend a lot of time trying to do behaviour modification because obviously, that's going to undermine their nutrition status. […] So we do try to keep the patient's goals in mind but we definitely don't want to concede too much especially if it's to their determent, so lots of times it's just trying to change people's mindset to make sure that they have a good understanding of the rationale for the recommendations and ultimately how it's supposed to improve their overall well-being and health.* (RD3)

5.2.4.2 Sources of Information. Dietitians frequently cited using Practice-based Evidence in Nutrition (PEN) handouts. PEN has handouts specific to a variety of topics, including eating guidelines for a person with an ileostomy and another handout for a person with a colostomy. Dietitians cited how they may also use handouts related to general healthy eating, hydration, etc.

> *So, all of the information that I would use comes from the Dietitians of Canada website [PEN] just so that we're giving consistent information. So that's the basis of my teaching [….], and I'll go follow that up with information about managing diarrhea or managing constipation or again [it] depends on what kind of state they came in. They may be malnourished, and they may need some information about how to add extra calories or how to get extra protein to help healing and those kinds of things.* (RD1)

> *[I use] the PEN nutrition handout, typically it's just like healthy eating guidelines for people who have an ileostomy. A lot of times I will go over you know, just general healthy eating guidelines and also kind of talk about what a higher fibre*

> *diet looks like as well, and also go over hydration guidelines.* (RD6)

Some dietitians used other sources of information, such as a handout created by their regional health authority or a resource from the Academy of Nutrition and Dietetics.

> *So, the guidelines that I'm currently using here is – we actually have an oncology tool kit that our program purchased from the Academy of Nutrition and Dietetics now it is American, and we always like to individualize it to, you know if there's food there that Newfoundlanders don't eat, or we add in the foods that they do eat. But we do find that the toolkit from the American group is really, really good and so we use that for a lot of our handouts that we use here with our program.* (RD5)

5.3 Interpretation of Findings

5.3.1 Introduction

This study provides us with a better understanding of the care that is provided to people with ostomies and the roles of each HCP. There are many members of the health care team and community who provide care and support to people living with ostomies. Table 5.3 summarizes each HCP's involvement in the care timeline, focus of care and setting of care, as found in this study. The amount of follow-up provided by each HCP in the outpatient setting largely varies due to several factors such as the routine of the HCP, the community of residence of the patient, the disease and treatment status of the patient, and complications and health care needs of the patient.

Table 5.3

Provider Roles and Delivery of Care

	Physician	**Nurse**	**Dietitian**	**Support Group**
Timeline of Involvement				
Pre-hospital	■			
Inpatient (Pre-surgery)	■	■		
Surgery (Post-surgical care)	■	■		
Discharge (Education)	■	■	■	
Outpatient	▨	▨	▨	
Community		▨		■
Concerns/Focus of Education				
Disease-specific care	■			
Surgery	■	■		
Stoma care	■	■		■
Managing ostomy appliance		■		■
Managing ostomy output		■	■	■
Nutritional needs		■	■	■
Sex and intimacy		■		■
Financial considerations		■		■
Lifestyle		▨		■
Coping/mental health		▨		▨
Care Setting				
Hospital admission	■	■	■	
Ambulatory care		■	▨	
Community		▨		■

Saturated colours indicate areas of consistent care, whereas pale colours indicate that some level of care is provided, but it is inconsistently offered and less prominent.

5.3.2 Physicians

Physicians are primarily involved before hospital admission for the care of the underlying condition and when a plan for surgery is made. Physician care specific to ostomies is primarily in the hospital setting and narrowly focused on the disease-specific needs/treatment, surgery, and stoma healing. Physicians were not generally aware of community-based support and often referred to the NSWOC for other patient supports.

5.3.3 Nurses

Nurse involvement with patients generally began in the hospital settings where they provide pre-operative and post-operative care, but often continue to provide support in out-patient and community settings. Nurses provided a key role in teaching patients about their stoma, ostomy appliance, and offered relevant health education. Nurses offered holistic care that addressed various needs and concerns of people with ostomies and are involved in marking the placement of the stoma, post-operative care, stoma care as well as helping the patient cope with financial, lifestyle, and mental health challenges.

5.3.4 Dietitians

Dietitians provide care primarily in in-patient settings (although some may see people with ostomies in an outpatient setting as well). Dietitians have a narrow focus and are routinely focused solely on managing ostomy output and nutritional needs.

Our findings highlight areas where dietitians could make a greater contribution to caring for people with ostomies. Firstly, dietitians' counselling was focused on educating patients on how to troubleshoot issues that could be experienced by a person with an ostomy. Dietitians provided similar dietary advice and information to patients concerning foods to avoid to minimize constipation, diarrhea, blockages, odour, or gas. Many dietitians used PEN handouts to relay this information. This instruction was usually first given after surgery while the patient was still in the hospital, and patients who were not seen in the cancer care clinic were unlikely to receive follow-up care. Dietetic counselling was rarely provided before surgery, but physicians and NSWOCs consistently agreed that pre-operative education is ideal for good patient care. Pre-operative counselling is supported by current research in nursing (Harris et al., 2020), but has not been investigated within dietetics to date.

Dietitian participants had varied perspectives on their role in supporting a patient who is having difficulty coping with changes caused by their ostomy. Some participants described their role as ‘nutrition only’ and focused on nutritional needs and foods to avoid or include in a patient’s diet. However, many dietitians discussed how a patient’s unwillingness to accept life with their ostomy or poor mental well-being created challenges that undermined their nutritional status and impeded the effectiveness of dietetic counselling. Participants explained that patients who did not cope well with having an ostomy were less engaged in dietetic counselling and/or reluctant to adjust their diet. While some dietitians tried to comfort patients to help them cope with their life changes, many commented that they did not feel adequately trained or equipped to handle patients’ psychosocial concerns and that more mental health resources are needed for patients with ostomies. The literature suggests that all HCPs should play an active role in helping patients with ostomies cope during self-management by identifying strategies aimed at solving ostomy-related problems and creating goals together (Lopes & Decesaro, 2014). Participants’ lack of preparedness to help patients cope with psychosocial concerns and offer holistic care underscores the need to re-examine the training provided to dietitians, and to develop interventions such as training workshops to help ensure dietitians feel capable of navigating psychosocial concerns and offering meaningful dietetic counselling.

5.3.5 Support Group Leaders

Support groups provide holistic care in community settings. Interestingly, ostomy support groups were well-known to NSWOCs, but many other HCPs were not familiar with the groups or involved in referring patients to them. Although some HCPs had participated in the groups as guest speakers, most HCPs did not discuss support groups with their patients. NSWOCs and support group leaders described similar benefits of support groups that have been outlined by other NSWOCs and researchers, such as the ability to learn from one another and to support acceptance of having an ostomy (Byfield, 2020; Cross & Hottenstein, 2010). Further, support group leaders were frustrated by the lack of HCP support and believed that more HCPs (not only NSWOCs) should be sharing information about support groups and encouraging people to attend. Similar frustrations around recruitment have been documented elsewhere, and researchers estimate that only half of eligible patients are being provided with ostomy support group information while in hospital in the United States (Miller, 2020; Schimmelpfenning, 2009).

5.3.5 Gaps in Care

This study highlighted several gaps in the current model of ostomy care in NL.

5.3.5.1 Psychosocial Support. Patients face new demands and challenges when they are adjusting to life with an ostomy and learning to self-manage their condition. Physicians and dietitians did not feel they had the skills and expertise to provide emotional and psychosocial support for patients with ostomies Several participants highlighted the difficulty in accessing counselling for patients due to lengthy wait times, time-consuming paperwork, and a lack of personnel dedicated to helping patients after surgery.

5.3.5.2 Collaborative Models of Care. We found a lack of a collaborative model of ostomy care. The majority of care for a patient with an ostomy is provided while they are in hospital and is primarily focused on clinical outcomes as opposed to psychosocial and behavioural outcomes. There is also a lack of focus on the care that is provided in the outpatient and community settings, including a lack of coordination with the family physician and limited involvement in ostomy support groups. These findings suggest that a more holistic approach is needed, especially after patients are discharged from the hospital.

Study results also indicate that care is often provided in discipline or sector-specific silos. Participants often worked independently and were not always familiar with what care is provided by other HCPs or how to access services, such as outpatient dietetic counselling services for people with non-cancerous diseases. Moreover, not all participants believed that their role included helping a patient come to terms with having an ostomy. The literature suggests that the shared goal of HCP team members should be that patients will cope with the changes they face and that their self-management will become an everyday routine that is not disruptive to their life, minimizes complications, and allows them to have the best QOL possible for that individual (Lopes & Decesaro, 2014).

5.3.6 Strengths and Limitations

This study has several strengths related to its design. Firstly, health care for people with ostomies is a complex topic because there may be various underlying conditions and needs involved. The qualitative nature of this study allowed us to collect data on a range of experiences and perspectives. We also had a wide range of participants. We interviewed HCPs with different roles and professional designations who had experience in a variety of work settings. We also included leaders from community-based ostomy support groups. The array of experiences and perspectives allowed us to get a holistic view of the health care that people with ostomies receive, and to also capture many subtle differences and similarities amongst patient groups. The study provides unique insight into patients' experiences of dietetic counselling for those with ostomies, especially within NL. These data provide relevant and contextual information to our local health care system.

There are also several limitations to this study. NL is a large province with four regional health authorities and care may differ across communities (Appendix J). It is important to note that Eastern Health contains NL's only tertiary services and the majority of cancer treatment and diagnostic services (Newfoundland and Labrador Medical Association, 2016). Because of the complexity of care for people with ostomies, most surgeries happen in hospitals in urban areas of the province and care may be similar in urban hospitals; however, patients who return home to rural areas after surgery may receive different care within the community in which they live. Despite efforts to recruit widely across the province, there were few participants from rural areas and none from the Labrador-Grenfell health authority. We also had a limited number of community-based health care professionals and did not include community liaison nurses and community nurses, family physicians, social workers, and pharmacists.

6.0 Discussion

6.1 Introduction

This thesis comprises three studies that used different approaches to examine the experiences and health care of people with ostomies. First, we conducted a thematic analysis of Reddit posts discussing food and nutrition made by people with ostomies. In the second study, we used interviews to explore patients' food-related needs for self-management. The third study consisted of interviewing health care professionals and support group leaders who provided care for people with ostomies, including dietitians, nurses with specialized ostomy training, and physicians. The analysis of Reddit data provided a better understanding of the concerns of people with a new ostomy, while interviews with patients in Newfoundland and Labrador (NL) gave a better understanding of the concerns of people who have lived with an ostomy long-term. The use of both global and local data provided insight into how experiences differ among subgroups of a diverse population (e.g., differences between age groups, diagnosis, type of ostomy, partner status, and/or connection to a peer support group). The health care provider (HCP) study identified how dietitians, nurses, physicians, and support group leaders contribute to the process of adaptation to living with an ostomy. The patient study and the HCP study also enabled us to compare patient and provider perspectives of health care for people with ostomies in NL.

6.2 Overview of Findings

Adjusting to life with an ostomy is a complex process, and peoples' experiences differ depending on their personal characteristics, health status, and environment. As a result, there is a large amount of literature focused on detailing the challenges faced by people living with ostomies and measuring their quality of life (QOL). However, there is a lack of literature describing specific nutrition and food-related concerns, interactions between HCPs and people with ostomies (including dietetic counselling), and how HCPs meet the needs of people with ostomies. This thesis has helped to fill this gap by describing the nutrition and food-related concerns of people living with ostomies, the current model of care for people with ostomies, the interactions of the interdisciplinary health care team, and patients' experiences of dietetic counselling.

Similar to previous studies, we found that people with ostomies were commonly concerned with controlling output (i.e., preventing leaks, blockages, odour, gas), and had challenges related to their body image, sexuality, mental health, travelling, and ability to sleep (Baldwin et al., 2009; Brown, 2017; Brown & Randle, 2005; Claessens et al., 2015; Di Gesaro, 2016; Kimura et al., 2017; Näsvall et al., 2017; Ramirez et al., 2014; Sasaki et al., 2021; Thorpe & McArthur, 2017). While few researchers have documented the food- and nutrition-related concerns of people with ostomies, we observed some parallels to previous research. For instance, as cited in other studies, participants with ostomies frequently avoided foods such as popcorn, lettuce, raw vegetables, and nuts to prevent blockages (de Oliveira et al., 2018; Floruta, 2001; Richbourg, 2014; Sun et al., 2014). Some participants also described changes in their eating patterns to minimize output during outings, similar to the findings of other researchers (Sun et al., 2014; Thorpe & McArthur, 2017).

Many ostomy-related studies were designed to measure the impact that an ostomy has on a person's QOL, and several researchers have found that QOL is negatively impacted after ostomy surgery (Brown, 2017; Brown & Randle, 2005; Kimura et al., 2017; Näsvall et al., 2017, Vonk-Klaassen et al., 2016). While we did not measure QOL directly like other researchers, our participants frequently described how their ostomy either negatively or positively affected their QOL. For example, several people indicated that their ostomy had a positive impact on their QOL by controlling symptoms and allowing them to manage their disease, therefore, they were able to participate in everyday activities that were previously a struggle due to their disease symptoms. Others, however, described that their ostomy had negatively impacted their QOL because they experienced symptoms such as pain, had difficulty controlling output and managing their appliance, or struggled to do everyday activities due to worry about their ostomy. Some Reddit users cited that they were depressed and a few disclosed that they experienced suicidal ideation. These contradicting experiences suggest that QOL impacts can greatly vary between subgroups and these differences should be further explored.

6.3 Model of Care

The second objective of the thesis was to describe the model of care for people with ostomies in NL. The Expanded Chronic Care Model (ECCM) provides a useful framework to describe the organization of the community, health care, and existing resources and policies for care for people with ostomies in the province. The ECCM illustrates how the organization of communities, health care, and existing resources and policies influence the health and well-being of people living with a chronic disease (Barr et al., 2003). The health system components of the ECCM include self-management/personal skills, delivery system design, decision support, and information systems.

6.3.1 Self-Management/Develop of Personal Skills

Within health care, there is a strong focus on training people with ostomies on how to take physical care of their ostomy. This training was typically provided by a nurse specialized in wound, ostomy, and continence (NSWOC) and frequently involved a community health nurse in the days immediately after a person returned home following their ostomy surgery. Components of education included learning how to change the ostomy appliance, how to empty the ostomy bag throughout the day, how to shower with an ostomy, skincare around the stoma, and knowing when to seek medical attention for their ostomy. Dietitians educated people about the effect that certain foods may have on output and provided lists of food that prevented diarrhea, constipation, gas, odour, and blockages. Physicians were primarily concerned with the health and function of the stoma and controlling symptoms of the underlying disease and its treatment.

6.3.2 Delivery System Design/Re-orient Health Services

As discussed in chapter five, the model of care for a person with an ostomy varied depending on their diagnosis. For individuals with cancer, care was usually offered from an interdisciplinary cancer centre, and the team regularly included nurses, physicians, dietitians, and other allied health professionals as appropriate (e.g., social workers, pharmacists, etc.). For those with inflammatory bowel disease (IBD), care was more segmented – a person was followed by a gastroenterologist and referrals for other HCPs were external to the gastroenterology clinic. Regardless of disease type, when a person was admitted for surgery, they were followed by their surgeon, an in-patient dietitian, a community liaison nurse, and connected with an NSWOC. Coordination between HCPs was variable, especially during the transition to an out-patient setting and for those with

IBD. For example, several HCPs were unsure of dietitians available in the out-patient setting, how patients could access them, or indications that would warrant a referral.

In terms of community services, people with ostomies would usually be seen by a community health nurse after discharge from the hospital to support a person learning to self-manage their ostomy at home. Within NL, there is one NSWOC who is positioned in the community setting and cares for people who have been discharged from surgical follow-up. People with ostomies may seek care at the community health centre or the NSWOC may travel to the person's home. NSWOCs also liaise with ostomy peer support groups and are typically the only HCP who refer people to those groups; support group leaders felt that not enough was being done within the health care system to inform people about the support groups and encourage attendance. Currently, four ostomy support groups exist in NL and given the province's sparse population that covers over 358,000km^2, there may be people unable to avail of such groups due to their location (Statistics Canada, 2022). Two groups offer a Facebook group where people with ostomies can connect virtually.

Typically, HCPs focused on caring for a person's physical health. Therefore, education was aimed to improve physical health outcomes and less attention was given to helping an individual develop coping skills to protect their mental health and well-being. With the exception of NSWOCs, HCPs frequently reported that their role did not involve providing support for psychosocial adaptation to life with an ostomy. Several HCPs reported offering general comfort to people or sending a referral to another professional (i.e., social worker or psychologist) for this concern, while some individuals admitted that they had not considered what role they may play in supporting psychosocial elements of adaptation to life with an ostomy

6.3.3 Decision Support

Existing best practice guidelines for caring for people with ostomies are intended for evidence-based nursing practice (Registered Nurses' Association of Ontario, 2019). Dietitians frequently cited using patient handouts from the Practice-Based Evidence in Nutrition (PEN) database. The PEN database is a subscription-based online knowledge translation tool used by the British Dietetic Association, Dietitians Australia, and Dietitians of Canada. PEN has a practice guidance toolkit about ostomies, that is focused on dietary interventions to prevent odour, gas, malnutrition, dehydration, constipation, and blockages (PEN, 2020). This toolkit does not discuss the challenges of adapting to life with an ostomy and the subsequent considerations a dietitian should make when counselling a person with an ostomy. Some of our dietitian participants stated that they used other resources from the Academy of Nutrition and Dietetics (United States organization) or handouts developed by other hospitals.

6.3.4 Information Systems

The use of information systems was rarely discussed by HCP participants, so it is unclear how current systems function and contribute to the delivery of health care. However, one participant discussed how they have access to a system within the cancer centre that allows HCPs to communicate with one another within a patient's chart. For example, if a dietitian needed to speak to a physician about a patient, they could set a reminder for the physician on the patient's chart and mark it urgent if needed. This system may differ from what is used outside of the cancer centre. Research has indicated that information systems, particularly those that use clinical reminders, may improve health care performance measures and result in timely initiation of recommended practices (Pasricha et al., 2013).

The community components of the ECCM include healthy public policy, supportive environments and community action.

6.3.5 Build Healthy Public Policy

The ECCM component *Build Healthy Public Policy* includes the development and implementation of policies designed to improve population health. For people with ostomies, healthy public policies include improving the affordability of ostomy supplies and supporting people in their employment.

For people with ostomies, the affordability of ostomy supplies is a longstanding issue, and this concern was heard across all three studies. This is worrying, given that having a low income has been associated with poorer health-related QOL, poorer psychological well-being, and poorer adjustment (Bekkers et al., 1997; Horner et al., 2010; Krouse et al., 2009; Lundy et al., 2009). As HCPs in chapter five explained, if individuals with a low income face additional stress due to the cost of ostomy supplies, this may in turn affect their psychological well-being and/or cause stoma complications due to insufficient management of their ostomy due to limited supplies. Researchers estimate that Canadians with ostomies spend a minimum of $1560 on ostomy supplies each year, this figure can be much higher if an individual experiences skin irritation (LeBlanc et al., 2019). Many people in Canada pay out-of-pocket for some, if not all, of their ostomy supplies (LeBlanc et al., 2019). Support group leaders discussed advocacy to address the financial burdens of having an ostomy by increasing government coverage of ostomy supplies, and by helping members avail of the disability tax credit. HCPs also voiced concerns about the affordability of supplies, especially for vulnerable populations.

Currently, there are programs to assist low-income people living with an ostomy in NL – the 65Plus Plan, the Foundation Plan, and the Special Assistance Program (Government of NL, n.d.; Western Health, 2016). The 65Plus Plan covers 75 percent of the cost of ostomy supplies for residents ages 65 and above, who receive Old Age Security Benefits and the Guaranteed Income Supplement; whereas the Foundation plan covers 100 percent of the cost of ostomy supplies for residents receiving income support (Government of NL, n.d.). People can apply to the Special Assistance Program through their regional health authority which consists of a financial and clinical assessment to confirm they are eligible for the program and the amount of coverage will be decided based on income (Western Health, 2016). While these programs provide financial relief for some populations, there is a disproportionate financial burden on people with an ostomy who have modest incomes that exceed thresholds for government support programs (i.e., the working poor). Screening for eligibility and preparing paperwork for such programs also require additional time and effort from HCPs and patients.

Lastly, our findings indicate that going to work can be stressful for people with ostomies. Participants frequently cited fear of leakages while at work, changed workplaces or left the workforce, and some described how they needed to use sick leave to care for their ostomy when complications arose. Paid sick leave policies may also benefit people with ostomies to remain in the workforce.

6.3.6 Create Supportive Environments

Like Thorpe and McArthur (2017), we identified that partners, family members, and friends were key sources of support for people adjusting to life with an ostomy. Most participants of the patient study had long-term partners throughout their time adjusting to their ostomy and described how their partners were crucial sources of support by offering reassurance, helping with the appliance, and by not seeing their ostomy as a barrier to attraction and sexual intimacy. We also found that nurses, namely NSWOCs, were an important source of support for a person with an ostomy. This finding was expected given the specialized ostomy training of these nurses and preliminary research indicating that patient education interventions that involve NSWOCs improve patient outcomes such as ostomy adjustment, self-management skills, and complications rates (Karabulut et al., 2014; Krouse et al., 2016; Zhang et al., 2013). Participants of our studies also reported that NSWOCs were frequently involved in ostomy peer support groups; this finding is unsurprising given that NSWOCs have taken a lead role in support groups elsewhere, and are encouraged to be engaged in such groups (Cross & Hottenstein, 2010; Mowdy, 1998).

Ostomy peer support groups promoted self-management and coping skills for wellness in several aspects. First of all, the format and topics of support group meetings were directed by the questions and concerns that members shared. Support group leaders ensured that there was an opportunity to provide input on guest speakers and events so that relevant information and support were available. Leaders described how meetings often included discussions of physical care and ostomy appliances, but people also talked about the challenges they faced with their ostomy and how it impacted their mental well-being. Similar to findings of support group research in the United State, people with ostomies commented on how peers provided tips and advice to manage their ostomy while performing everyday activities and shared how they could relate to another person's situation (Byfield, 2020). The overarching goal of support groups was to help people accept their ostomy and develop coping strategies so they could *live well with their condition*. This is arguably different from the view of self-management shared by many HCPs, that the purpose of self-management was to control disease. Bioethicists such as Entwistle et al. (2018b), have highlighted how an ethical and person-centred approach to self-management should be oriented to help a person live well with their chronic condition, rather than to manage their condition well. This approach can (and typically does) involve biomedical components of controlling disease, but it also involves considerations of a person's values and identity.

Peer ostomy support groups had some linkages with the health care system, typically through an NSWOC. Some other HCPs reported attending support groups in the past as guest speakers, while some were unaware of existing groups. Support group leaders believed that people receiving ostomy surgery were not always given support group information prior to hospital discharge and wanted more involvement of HCPs to refer patients. It is unknown how frequently people with ostomies in Canada are referred to support groups, but this has been determined as an issue within the United States (Miller, 2020). It is believed that ostomy support groups help individuals process change more effectively (Byfield, 2020). Future research should explore HCP involvement in support groups, factors related to participation in support groups, and formats of support groups that people with ostomies prefer; such research would allow us to better understand how support groups should be offered for various patient demographics (e.g., in-person, online, in a hospital setting, etc.). Support groups that have strong relationships with HCPs and health care organizations may be well suited to address the needs of their community and advocate for people with ostomies (Byfield, 2020).

We also identified areas of support that were not previously identified in the literature, namely the workplace environment and ostomy supply companies. After recovering from surgery, participants were faced with having to return to work while managing their ostomy. This was a daunting transition for some; participants were worried that they would experience mishaps with their appliance, and they were concerned about the distance to the washroom and the privacy of washrooms. Some felt that their employer was very supportive, while others felt that their employer was not sympathetic to their needs (i.e., using sick days due to their ostomy). Several participants left their workplaces due to their ostomy concerns.

Ostomy supply companies played a role in supporting participants by offering free samples and free programs with professionals dedicated to supporting people with an ostomy (e.g., Coloplast Care, Hollister Secure Start). Supply companies seemed to have strong connections with ostomy peer support groups and offered webinars; some group members became supply representatives. Finding the best fitting ostomy appliance was important to participants, and several people discussed how trying new products (e.g., discreet appliances, odour control sachets, etc.) helped them feel more comfortable with their ostomy.

Participants with ostomies often discussed the importance of knowing where to find public washrooms while being away from home, whether it be at work, shopping, or during travel. Private washrooms (as opposed to stalls) were preferred by some people with ostomies so that they could discreetly care for their ostomy. When emptying an ostomy bag, sometimes people may need access to water to rinse their ostomy clip, and while not required, many ostomates prefer to rinse their ostomy bag itself using a bottle of water (Valtolina, 2021). Therefore, supportive environments for people with ostomies would include private washrooms, such as accessible family washrooms. Additionally, Colostomy UK advocates for stoma-friendly washrooms that include hooks to hang clothing and purses, shelf space so people can spread out their supplies on a sanitary surface, mirrors so people can see their stoma, and a discreet disposal bin (Colostomy UK, 2020).

6.3.7 Strengthen Community Action

Non-profit organizations that support people with ostomies have also worked to raise awareness about ostomies to decrease stigma, through campaigns such as *Uncover Ostomy* (Frohlich & Zmyslinki-Seelig, 2016). When a person is faced with ostomy surgery, they often begin to worry about being stigmatized (Savard & Woodgate, 2009). Within our studies, people often worried about stigma; some did not want others to not know that they have an ostomy, changed how they dress, were uncomfortable in swimwear, worried about seeking intimate relationships, and worried about being treated differently by those around them.

6.4 The Role of the Dietitian

The thesis also examined the role of dietitians and their interactions within an interdisciplinary health care team to provide care to people with ostomies, the current practices of dietitians who counsel people with ostomies, and patients' experiences of dietetic counselling. Dietitians were regularly involved in in-patient care immediately after a person had ostomy surgery, and follow-up care was variable. During in-patient care, dietitians were focused on educating people with ostomies about foods to avoid while recovering from surgery and how to manage common symptoms. Dietitians encouraged people to reintroduce foods over time and take notice of their effect, promoting a trial-and-error approach. In-patient dietitians rarely referred people to an out-patient dietitian after discharge from the hospital. People with ostomies who had cancer often received follow-up care from dietitians in the cancer care centre, while those with a non-cancerous disease did not have follow-up care with a dietitian. The model of care for this population should be reassessed and regional health authorities should develop standards of care that describe indications for follow-up and discharge from care.

Dietetic counselling for people with ostomies was largely focused on biomedical goals and disease control. Dietetic counselling was typically focused on nutritional status and instruction on foods to eat or avoid because of an ostomy. Overall, there was little discussion of helping people cope with dietary changes within the context of their day-to-day life (e.g., being unable to eat foods they previously enjoyed, preparing and cooking meals differently, having to be constantly conscientious, etc.). Dietitians noted that some people struggled to accept their ostomy, which undermined their ability to follow nutrition recommendations. However, many dietitians did not feel equipped to help a person cope with changes, and some expressed that psychosocial support was outside their scope of practice. These findings are consistent with the lack of discussion of psychosocial adaptation in dietetic literature. Futher, these findings indicate a need to reexamine dietetic education and training to help dietitians feel prepared.

To ensure a patient has a good QOL while managing their condition, dietitians should focus on QOL outcomes as well as clinical outcomes and adapt their counselling based on the individual. For example, dietitians should consider a person's favourite foods, cooking ability, household, routines, finances, and comorbidities. This view aligns with creators of both the Organizational Framework for Exploring Nutrition Narratives (OFFENN) and the Collaborative, Client-Centred Nutrition Education (3CNE) Framework which place an emphasis on individualistic counselling (Morley, 2016; Morley et al., 2016). Further, dietitians should have a better understanding of the challenges related to having an ostomy and know how to support people to mitigate those challenges. Information about how ostomies impact peoples' lives, important considerations for HCPs, and guidance on how dietitians can support psychosocial adaptation should be included in dietetic training and decision-making support such as PEN and best practice guidelines.

6.5 Recommendations for Health Care Providers

After mapping our results to the ECCM, our findings highlight gaps and areas for improvement within the current model of care for people with ostomies, leading us to several recommendations for HCPs:

1. Support self-management by providing person-centred care that considers the individual characteristics and the identity of the patient.
2. Develop a chronic disease management program for people with ostomies that extends beyond the hospital and offers support within the community setting.
3. Build structure and processes within health care settings to support interdisciplinary care for people with ostomies.
4. Address lack of mental health resources by increasing the number of mental health professionals available to people with ostomies, ensuring that these services are covered by the provincial medical health insurance plan.
5. Develop clinical dietetic guidelines for people with ostomies.

6. Enhance information systems to support long-term care (i.e., automatic reminders to provide follow-up).
7. Support healthy public policy for people with ostomies such as initiatives to increase coverage of ostomy products.
8. Support local ostomy support groups and build partnerships to create supportive environments by efforts to reduce ostomy-related stigma, such as advocating for stoma-friendly washrooms.

6.6 Future Research for People with Ostomies

While common challenges of people with ostomies are well documented (i.e., fear of leakages, impact on body image, sexuality, etc.), future research should investigate the quality of care for people with ostomies. For example, quality assurance studies would allow us to better understand how care can be improved, and how patient experiences in NL vary from other areas. Epidemiological studies are needed to collect demographic data and measure patient outcomes such as hernia development, blockages, complications requiring hospitalizations and surgeries, QOL, and patient satisfaction. Information on the quality of existing programs could identify populations at risk of particular outcomes so that risk-prevention measures could be developed, and organizations could improve standards of care. While a documentary analysis was beyond the scope of this thesis, interviews with HCPs did highlight commonly used resources that could be included in future analyses. Now that the needs of people with ostomies in NL are better known, a documentary analysis of handouts and education tools should be conducted to assess the appropriateness and comprehensiveness of the patient resources that HCPs use. Notably, our studies highlight differences in experiences of people with ostomies who have different diseases, particularly differences between those with cancerous and non-cancerous diseases. Future studies are needed to better understand how experiences are similar, how they differ, and factors affecting these experiences. These differences should be considered when evaluating the quality of care delivered to people with ostomies and assessing the appropriateness of handouts and education tools for each population.

My thesis included interviews with nurses, dietitians, support group leaders, and physicians who specialized in surgery, gastroenterology, or oncology. Future research in this area should investigate the roles of other providers such as family physicians, community liaison nurses, community health nurses, and social workers; a better understanding of these roles would provide us with a more holistic view of health care for people with ostomies. Similarly, further research on the role of ostomy supply companies will reveal how their existing programs (e.g., Coloplast Care, Hollister Secure Start) provide care to people with ostomies and how care is coordinated with NSWOCs in the health care system.

Research is also needed to better understand stigma related to ostomies, including an investigation of perceived stigma from people with ostomies and perceptions of people without ostomies. A better understanding of stigma will inform the development of campaigns to reduce stigma and the impact of stigma reduction programs on people's adaptation to life with an ostomy. Similarly, research regarding stoma-friendly environments (i.e., workplaces, public spaces, etc.) will identify ways to improve accessibility and support people with ostomies to participate in everyday activities.

6.7 Future Research in Dietetics

This thesis adds to our current understanding of dietetic counselling for people in

NL who live with ostomies and identified where further research is needed to improve care. A longitudinal study of people with ostomies that analyzes dietitian-patient interactions from the first point of contact would provide us with a comprehensive overview of how care is provided over time and the perspectives of people new to life with an ostomy. Further, studies examining people with ostomies and other comorbidities are needed to identify how dietetic counselling should be adapted to meet the needs of people with multiple chronic illnesses.

To determine the quality of care provided by dietitians, research should involve analysis of elements that contribute to person-centred care such as four aspects identified by Burton et al. (2017): information, situation, living well, and communication style. *Information* refers to an HCP providing personally relevant information as opposed to providing everyone with the same information; an individualistic approach is supported by the nature of bowel conditions and variation between symptom management for different people. The element *situation* means taking into account personal circumstances such as where one lives, finances, and household members when offering suggestions to patients. *Living well* is an attribute of care in which the HCP works to determine what a patient values in their life, how they like to spend their time, and the kind of person they'd like to be, and then incorporates that information to tailor the care provided. Lastly, *communication style* relates to how an HCP communicates with a person; friendly, personal communication is preferred in person-centred care. By evaluating perceptions of people who receive dietetic counselling we can highlight areas where improvement of care is needed to achieve person-centred care. Future research should further evaluate how the 3CNE framework and OFFENN can be used to improve dietetic education and training by grounding dietetic practice in peson-centred values (Morley, 2016; Morley et al., 2016).

6.8 Strengths and Limitations

This thesis used multiple approaches to gather an in-depth understanding of the experiences of people with ostomies and provides novel insight; this research was the first to study the experiences of people living with ostomies in NL. We collected global social media data from Reddit and conducted local key informant interviews with people who live with an ostomy, ostomy support group leaders, and HCPs who care for people with ostomies in NL. Our first study used innovative research methods to analyze social media discourse on Reddit, methods that we have not identified as used in current health research. Our pragmatic approach influenced our research design and decisions throughout our process. For instance, we included a variety of health care providers, specifically those with one year of experience at minimum, and included support group leaders to get a holistic view of care and supports. We recruited participants from across the province in both urban and rural settings, and used system-focused and dietitian-focused terminology. Further, our interview questions were broadly focused to explore context, and we asked beyond health services to obtain a holistic view which was further supported by our use of the ECCM as our theoretical framework (Barr et al., 2003).

We also took several measures to ensure trustworthiness across all three studies by addressing each criterion of trustworthiness outlined by Guba and Lincoln (1994): credibility, dependability, confirmability, transferability, and authenticity. To establish credibility, we performed iterative questioning of the data by revisiting initial findings and we held regular debriefings between members of the research team, and discussed out findings with peers (Connelly, 2016; Given, 2008; Shenton, 2004). Credibility was also strengthened by the use of well-established methods of thematic analysis (Braun & Clarke, 2006), engaging with people who have ostomies and HCPs throughout the research studies to become familiar with the context and culture, using two initial coders, and maintaining a reflective journal (Connelly, 2016; Green & Thorogood, 2018; Lincoln & Guba, 1985; Shenton, 2004). We also performed "on-the-spot" member checking throughout interviews to ensure our understanding of participants' responses were correct (Shenton, 2004). Further, by using multiple approaches, we were able to triangulate our findings by comparing our results from each study which captured different perspectives and used different sources of data (Green & Thorogood, 2018; Shenton, 2004).

To establish dependability and confirmability, I maintained an audit trail of all research documents (i.e., transcripts, coding templates, etc.) and took detailed notes of our decision-making and processes (Connelly, 2016; Green & Thorogood, 2018; Nowell et al., 2017; Tobin & Begley, 2004). In addition, our use of triangulation allowed us to reduce investigator bias and improve confirmability (Shenton, 2004). We also provided a detailed description of methods, context, population, and geographic location to allow readers to determine if this thesis is transferable to other contexts (Connelly, 2016; Lincoln & Guba, 1985). Lastly, we sought authenticity by aiming to recruit an appropriate selection of participants with diverse experiences and illustrate a range of different realities (Polit & Beck, 2014) and we had good participation across multiple areas of NL when recruiting participants for interviews.

However, my thesis is not without limitations. First, our studies did not involve people in NL who are adapting to *new* ostomies – participants with ostomies who were interviewed had all lived with an ostomy for five or more years. Also, due to the sparse population in NL covering a large geographic area (approximately 510,550 people living across more than 358,000km^2), and differences in the distribution of health care resources across NL, we may not have fully captured the experiences of people living in remote and rural areas (Statistics Canada, 2022). Our findings may also be less applicable to those with temporary ostomies. Lastly, our three studies all used qualitative methodology to explore our topic, so while we have rich and contextual data, we are unable to generalize our results and make comparisons to other quantitative studies. Future research in this area in NL should involve a longitudinal study with a mixed methodology that includes a measurement of QOL.

7.0 Conclusion

Intestinal ostomies are common during the physical treatment of bowel diseases, and having an ostomy can cause changes in a person's life and affect their overall well-being. People with ostomies are frequently concerned about managing their ostomy, dietary changes, and being able to partake in daily activities such as social outings, and travel (Claessens et al., 2015; Thorpe & McArthur, 2017; Sun et al., 2014). While a person learns how to self-manage their ostomy, they may encounter challenges such as changes in body image, a decreased ability to sleep, and anxiety related to sexual relationships (Baldwin et al., 2009; Brown & Randle, 2015). The combination and interaction of experienced changes may affect one's mental health and explain why people with ostomies frequently cite having a lower quality of life (QOL) than their counterparts (Brown, 2017; Di Gesaro, 2016; Mols et al., 2014). Literature suggests that health care providers (HCPs) should provide holistic care that acknowledges the complexity of coming to terms with an ostomy and offer support to develop appropriate self-management strategies that are informed by the context, values, and preferences of people's lives (Burton et al., 2017; Lopes & Decesaro, 2014). However, dietetic literature only describes the physical health needs of people with ostomies and provides recommendations in isolation from other concerns.

Our results show that people with ostomies frequently struggle with accepting their ostomy and coping with changes, but also develop self-management strategies over time and receive support from multiple sources. To self-manage, people restrict particular foods and make dietary changes to manage output and minimize symptoms through a trial-and-error approach but may sometimes adopt unhealthy behaviours such as skipping meals to prevent output.

This thesis applied the Expanded Chronic Care Model (ECCM) to describe the model of care in Newfoundland and Labrador (NL) and examine how dietetic counselling is provided to people with ostomies within the health system and community, how dietitians interact with other team members and community members, and how current dietetic counselling in NL aligns with the needs of people with ostomies. People with ostomies sometimes find dietetic advice to be unrealistic or unhelpful for their situation because it does not align with the foods they enjoy or afford, or because individual experiences differ from one another, and general guidelines are not relatable. Further, dietitians and other HCPs such as physicians are primarily focused on physical health concerns and feel unprepared to navigate psychosocial concerns or believe that addressing psychosocial health concerns is not within their role. HCPs also noted that there is a lack of mental health resources and interdisciplinary, standardized care, particularly for those with non-cancerous diseases.

This thesis used novel methods to qualitatively analyze social media data that was then able to be compared to data collected locally; this research is a resource for researchers looking to conduct health research using social media data sources. Additionally, this thesis offered new insight into how care is provided to and received by people with ostomies in NL and the effectiveness of dietetic counselling for people with ostomies. Future ostomy research should build from this thesis and further investigate the quality of care for people with ostomies in NL by developing quality assurance studies to evaluate patient outcomes, exploring perspectives of additional HCPs (i.e., family physicians, social workers, etc.), investigating best practices of support groups, and identifying any differences that exist within other rural and remote areas of NL. Within dietetics, future research should involve longitudinal studies and patient-dietitian dyads to observe dietetic counselling and patient-provider relationships over time, analyze the person-centredness of dietetic counselling (Burton et al., 2017), and develop and evaluate dietetic training modules for dietitians who care for people with ostomies.

Additionally, policy and decision-makers within government and health care organizations should consider how communities and the health system can be improved for people living with ostomies. For instance, supportive environments for people with ostomies include stoma-friendly accessible washrooms, public policy should address the financial concerns of having an ostomy (i.e., cost of supplies, employment concerns), and health services should provide long-term, holistic, collaborative care that involves community members such as peer ostomy support groups.

Dietetic counselling for people with ostomies in NL should aim to provide a holistic approach that is informed by physical, psychosocial, and behavioural aspects of health, and is tailored to each individual. While future studies are needed in this area, this thesis provides a foundation and direction for future research and policy to improve the QOL of people with ostomies.

References

Alatab, S., Sepanlou, S. G., Ikuta, K., Vahedi, H., Bisignano, C., Safiri, S., . . . Naghavi, M. (2020). The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990–2017: A systematic analysis for the Global Burden of Disease Study 2017. *The Lancet Gastroenterology & Hepatology*, *5*(1), 17-30. https://doi.org/10.1016/S2468-1253(19)30333-4

Allemang, B., Sitter, K., & Dimitropoulos, G. (2022). Pragmatism as a paradigm for patient-oriented research. *Health Expectations, 25*(1), 38-47. https://doi.org/10.1111/hex.13384

Andersen, B. D., Keizerswaard, P. V., Castro, M. M., English, E., & Carter, D. (2011). Introduction to the DialogueStudy: Methods and baseline demographic findings. *Gastrointestinal Nursing*, *9*(Sup2), 4-8. https://doi.org/10.12968/gasn.2011.9.Sup2.4

Aronovitch, S. A., Sharp, R., & Harduar-Morano, L. (2010). Quality of life for patients living with ostomies: Influence of contact with an ostomy nurse. *Journal of Wound, Ostomy and Continence Nursing, 37*(6), 649-653. https://doi.org/10.1097/WON.0b013e3181f90d16

Atkinson, P. (2007). *Ethnography: Principles in practice*. Routledge.

Baldwin, C. M., Grant, M., Wendel, C., Hornbrook, M. C., Herrinton, L. J., McMullen, C., & Krouse, R. S. (2009). Gender differences in sleep disruption and fatigue on quality of life among persons with ostomies. *Journal of Clinical Sleep Medicine*, *5*(4), 335-343. https://doi.org/10.5664/jcsm.27544

Barr, V., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., &

Salivaras, S. (2003). The expanded chronic care model: An integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hospital Quarterly, 7*(1), 73-82. https://doi.org/10.12927/hcq.2003.16763

Barthel, M., Stocking, G., Holcomb, J., & Mitchell, A. (2016). *Seven-in-ten Reddit users get news on the site*. Pew Research Center's Journalism Project. https://policycommons.net/artifacts/618607/seven-in-ten-reddit-users-get-news-on-the-site/1599577/

Bekkers, M. J. T. M., Van Knippenberg, F. C. E., Van Dulmen, A. M., Van Den Borne, H. W., & van Berge Henegouwen, G. P. (1997). Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: A 4-year follow-up. *Journal of Psychosomatic Research, 42*(3), 235-244. https://doi.org/10.1016/S0022-3999(96)00288-7

Bernstein, C. N., Blanchard, J. F., Rawsthorne, P., & Wajda, A. (1999). Epidemiology of Crohn's disease and ulcerative colitis in a central Canadian province: A population-based study. *American Journal of Epidemiology*, *149*(10), 916-924. https://doi.org/10.1093/oxfordjournals.aje.a009735

Blackburn, K. G., Yilmaz, G., & Boyd, R. L. (2018). Food for thought: Exploring how people think and talk about food online. *Appetite*, *123*, 390-401. https://doi.org/10.1016/j.appet.2018.01.022

Bosshardt, T. L. (2003). Outcomes of ostomy procedures in patients aged 70 years and older. *Archives of Surgery*, *138*(10), 1077-1082. https://doi.org/10.1001/archsurg.138.10.1077

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative*

Research in Psychology, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brett, E. I., Stevens, E. M., Wagener, T. L., Leavens, E. L., Morgan, T. L., Cotton, W. D., & Hébert, E. T. (2019). A content analysis of JUUL discussions on social media: Using Reddit to understand patterns and perceptions of JUUL use. *Drug and Alcohol Dependence*, *194*, 358-362. https://doi.org/10.1016/j.drugalcdep.2018.10.014

Brown, F. (2017). Psychosocial health following stoma formation: A literature review. *Gastrointestinal Nursing*, *15*(3), 43-49. https://doi.org/10.12968/gasn.2017.15.3.43

Brown, H., & Randle, J. (2005). Living with a stoma: A review of the literature. *Journal of Clinical Nursing*, *14*(1), 74-81. https://doi.org/10.1111/j.1365-2702.2004.00945.x

Burton, C. D., Entwistle, V. A., Elliott, A. M., Krucien, N., Porteous, T., & Ryan, M. (2017). The value of different aspects of person-centred care: A series of discrete choice experiments in people with long-term conditions. *BMJ Open*, *7*(4), e015689. https://dx.doi.org/10.1136/bmjopen-2016-015689

Byfield, D. (2020). The lived experiences of persons with ostomies attending a support group: A qualitative study. *Journal of Wound, Ostomy and Continence Nursing*, *47*(5), 489-495. https://doi.org/10.1097/WON.0000000000000696

Canadian Cancer Society. (n.d.-a). *Canadian cancer.* https://cancer.ca/en/cancer-information/cancer-types/colorectal

Canadian Cancer Society. (n.d.-b). *Anal cancer.* https://cancer.ca/en/cancer-information/cancer-types/anal

Canadian Digestive Health Foundation. (2009). *Establishing digestive health as a priority for Canadians. The Canadian Digestive Health Foundation – National digestive disorders prevalence & impact study report.* https://cdhf.ca/digestive-disorders/diverticular-disease/statistics/

Canadian Interprofessional Health Collaborative. (2010). *A national interprofessional competency framework.* https://phabc.org/wp-content/uploads/2015/07/CIHC-National-Interprofessional-Competency-Framework.pdf

Candela, A. G. (2019). Exploring the function of member checking. *The Qualitative Report, 24*(3), 619-628. https://doi.org/10.46743/2160-3715/2019.3726

Chen, X., Lun, Y., Yan, J., Hao, T., & Weng, H. (2019). Discovering thematic change and evolution of utilizing social media for healthcare research. *BMC Medical Informatics and Decision Making,19(S2),* 39-53. *https://doi.org/10.1186/s12911-019-0757-4*

Chourasiya, S. (2022). *Meaning, definition, principles and characteristics of pragmatism.* https://www.samareducation.com/2022/10/pragmatism-philosophy.html

Cima, R. R. (2021). Parastomal hernia. *UpToDate.* Retrieved April 15, 2022, from https://www.uptodate.com/contents/parastomal-hernia

Claessens, I. M., Probert, R. D., Tielemans, C., Steen, A., Nilsson, C., Størling, Z., & Andersen, B. (2015). The Ostomy Life Study: The everyday challenges faced by people living with a stoma in a snapshot. *Gastrointestinal Nursing, 13*(5), 18-25. https://doi.org/10.12968/gasn.2015.13.5.18

Cleveland Clinic. (2019, September 27). *J-pouch surgery.* Cleveland Clinic.

https://my.clevelandclinic.org/health/treatments/21062-j-pouch-surgery

Colorectal Cancer Canada. (2019, May). *A guide to understanding an ostomy.* https://www.colorectalcancercanada.com/app/uploads/2019/05/A_Guide_to_Understanding_An_Ostomy.pdf

Colostomy UK. (2020). *Guide to stoma friendly toilets.* https://www.colostomyuk.org/wp-content/uploads/2020/09/Stoma-Friendly-Toilets-Guidelines.pdf

Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, *25*(6), 435. https://www.proquest.com/docview/1849700459?pq-origsite=gscholar&fromopenview=true

Cross, H. H., & Hottenstein, P. (2010). Starting and maintaining a hospital-based ostomy support group. *Journal of Wound Ostomy & Continence Nursing*, *37*(4), 393-396. https://doi.org/10.1097/WON.0b013e3181e45794

Dawson, B. (2016). *Diverticular disease and diverticulitis: Symptoms, treatment options and long-term health outcomes.* Nova Biomedical.

de Oliveira, A. L., Boroni Moreira, A. P., Pereira Netto, M., & Goncalves Leite, I. C. (2018). A cross-sectional study of nutritional status, diet, and dietary restrictions among persons with an ileostomy or colostomy. *Ostomy Wound Management, 64*(5), 18-29. https://doi.org/10.25270/owm.2018.5.1829

Del Pinto, R., Pietropaoli, D., Chandar, A. K., Ferri, C., & Cominelli, F. (2015). Association between inflammatory bowel disease and vitamin D deficiency: A systematic review and meta-analysis. *Inflammatory Bowel Diseases*, *21*(11), 2708-2717. https://doi.org/10.1097/MIB.0000000000000546

Derksen, C., Serlachius, A., Petrie, K., & Dalbeth, N. (2017). "What say ye gout experts?" A content analysis of questions about gout posted on the social news website Reddit. *BioMed Central Musculoskeletal Disorders, 18*(1), 488. https://doi.org/10.1186/s12891-017-1856-y

Di Gesaro, A. (2016). The psychological aspects of having a stoma: A literature review. *Gastrointestinal Nursing*, *14*(2), 38-44. https://doi.org/10.12968/gasn.2016.14.2.38

Dietitians of Canada. (2021). Cancer - Nutritional implications of treatment. *PEN.* Retrieved March 14, 2022, from https://www.pennutrition.com/KnowledgePathway.aspx?kpid=5935&trcatid=42

Donabedian, A. (1968). Promoting quality through evaluating the process of patient care. *Medical Care, 6*(3), 181-202. http://www.jstor.org/stable/3762934

Entwistle, V. A., Cribb, A., Watt, I. S., Skea, Z. C., Owens, J., Morgan, H. M., & Christmas, S. (2018a). “The more you know, the more you realise it is really challenging to do”: Tensions and uncertainties in person-centred support for people with long-term conditions. *Patient Education and Counseling, 101*(8), 1460-1467. https://doi.org/10.1016/j.pec.2018.03.028

Entwistle, V. A., Cribb, A., & Owens, J. (2018b). Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well. *Health Care Analysis*, *26*(1), 48-65. https://doi.org/10.1007/s10728-016-0335-1

Fichera, A. (2020). Restorative proctocolectomy with ileal pouch-anal anastomosis: Laparoscopic approach. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/restorative-proctocolectomy-with-ileal-pouch-anal-anastomosis-laparoscopic-approach

Fleshner, P. R. (2021a). Surgical management of ulcerative colitis. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/surgical-management-of-ulcerative-colitis

Fleshner, P. R. (2021b). Operative management of Crohn disease of the small bowel, colon, and rectum. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/operative-management-of-crohn-disease-of-the-small-bowel-colon-and-rectum

Floruta, C. V. (2001). Dietary choices of people with ostomies. *Journal of Wound, Ostomy, and Continence Nursing, 28*(1), 28-31. https://doi.org/10.1067/mjw.2001.112079

Francone, T. D. (2021). Overview of surgical ostomy for fecal diversion. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/overview-of-surgical-ostomy-for-fecal-diversion

Frohlich, D. O., & Zmyslinski-Seelig, A. N. (2016). How Uncover Ostomy challenges ostomy stigma, and encourages others to do the same. *New Media & Society*, *18*(2), 220-238. https://doi.org/10.1177/1461444814541943

Gautam, S., & Poudel, A. (2016). Effect of gender on psychosocial adjustment of colorectal cancer survivors with ostomy. *Journal of Gastrointestinal Oncology*, *7*(6), 938. http://dx.doi.org/10.21037/jgo.2016.09.02

Giacomini, M. (2010). Theory matters in qualitative health research. In I. Bourgealt, R. Dingwall, & R. De Vries (Eds.), *The SAGE handbook of qualitative methods in* *health research*, (pp.125-156). SAGE Publications, Inc. http://dx.doi.org/10.4135/9781446268247.n8

Giordano, V., Nicolotti, M., Corvese, F., Vellone, E., Alvaro, R., & Villa, G. (2020). Describing self-care and its associated variables in ostomy patients. *Journal of Advanced Nursing*, *76*(11), 2982-2992. https://doi.org/10.1111/jan.14499

Given, L. M. (2008). *The SAGE encyclopedia of qualitative research methods*. SAGE Publications, Inc. https://dx.doi.org/10.4135/9781412963909.n48

Government of Canada. (2018). *Tri-Council Policy Statement: Ethical conduct for research involving humans – TCPS 2.* https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html

Government of Newfoundland and Labrador. (n.d.). *Prescription Drug Program (NLPDP): Plan overview.* Health and Community Services, https://www.gov.nl.ca/hcs/prescription/nlpdp-plan-overview/

Government of Newfoundland and Labrador. (2019). Rural lens: Assessing regional policy implications, a guide for public bodies. https://www.gov.nl.ca/pep/files/Rural-Lens.pdf

Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., ... & Krouse, R. S. (2011). Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. *Oncology Nursing Forum, 38*(5), 587-596. https://doi.org/10.1188/11.ONF.587-596

Green, & Thorogood, N. (2018). *Qualitative methods for health research* (4th ed.). SAGE Publications, Inc.

Guba, E.G., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N.

Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). SAGE Publications, Inc.

Hadi, M. A., & José Closs, S. (2016). Ensuring rigour and trustworthiness of qualitative research in clinical pharmacy. *International Journal of Clinical Pharmacy*, *38*(3), 641-646. https://doi.org/10.1007/s11096-015-0237-6

Harris, M. S., Kelly, K., & Parise, C. (2020). Does preoperative ostomy education decrease anxiety in the new ostomy patient? A quantitative comparison cohort study. *Journal of Wound Ostomy & Continence Nursing*, *47*(2), 137-139. https://doi.org/10.1097/WON.0000000000000623

Hashash, J. A., & Regueiro, M. (2021). Medical management of low-risk adult patients with mild to moderate ulcerative colitis. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/medical-management-of-low-risk-adult-patients-with-mild-to-moderate-ulcerative-colitis

Holtrop, J. S., & Glasgow, R. E. (2020). Pragmatic research: An introduction for clinical practitioners. *Family Practice, 37*(3), 424-428. https://doi.org/10.1093/fampra/cmz092

Horner, D. J., Wendel, C. S., Skeps, R., Rawl, S. M., Grant, M., Schmidt, C. M., ... & Krouse, R. S. (2010). Positive correlation of employment and psychological well-being for veterans with major abdominal surgery. *The American Journal of Surgery*, *200*(5), 585-590. https://doi.org/10.1016/j.amjsurg.2010.07.006

Hou, J. K., Abraham, B., & El-Serag, H. (2011). Dietary intake and risk of developing inflammatory bowel disease: A systematic review of the literature. *Official Journal of the American College of Gastroenterology, 106*(4), 563-573.

https://doi.org/10.1038/ajg.2011.44

Hubbard, G., Taylor, C., Beeken, B., Campbell, A., Gracey, J., Grimmett, C., ... & Gorely, T. (2017). Research priorities about stoma-related quality of life from the perspective of people with a stoma: A pilot survey. *Health Expectations*, *20*(6), 1421-1427. https://doi.org/10.1111/hex.12585

Jelenko, U., & Kozjek, N. R. (2018). Improvement of nutritional status of patients with high-output ileostomy due to nutritional counseling. *Clinical Nutrition*, *37*, S303. https://doi.org/10.1016/j.clnu.2018.06.2059

Karabulut, H. K., Dinç, L., & Karadag, A. (2014). Effects of planned group interactions on the social adaptation of individuals with an intestinal stoma: A quantitative study. *Journal of Clinical Nursing*, *23*(19-20), 2800-2813. https://doi.org/10.1111/jocn.12541

Karlinger, K., Györke, T., Makö, E., Mester, Á., & Tarján, Z. (2000). The epidemiology and the pathogenesis of inflammatory bowel disease. *European Journal of Radiology*, *35*(3), 154-167. https://doi.org/10.1016/S0720-048X(00)00238-2

Kimura, C. A., Kamada, I., Guilhem, D. B., Modesto, K. R., & Abreu, B. S. D. (2017). Perceptions of ostomized persons due to colorectal cancer on their quality of life. *Journal of Coloproctology, 37*(1), 1-7. https://doi.org/10.1016/j.jcol.2016.05.007

Krouse, R. S., Grant, M., McCorkle, R., Wendel, C. S., Cobb, M. D., Tallman, N. J., ... & Hornbrook, M. C. (2016). A chronic care ostomy self-management program for cancer survivors. *Psycho-Oncology*, *25*(5), 574-581. https://doi.org/10.1002/pon.4078

Krouse, R. S., Herrinton, L. J., Grant, M., Wendel, C. S., Green, S. B., Mohler, M. J., ... & Hornbrook, M. C. (2009). Health-related quality of life among long-term rectal cancer survivors with an ostomy: Manifestations by sex. *Journal of Clinical Oncology*, *27*(28), 4664-4670. https://doi.org/10.1200/JCO.2008.20.9502

Kuper, A., Lingard, L., & Levinson, W. (2008). Qualitative research: Critically appraising qualitative research. *British Medical Journal*, *337*(7671), 687–689. https://doi.org/10.1136/bmj.a1035

Laghousi, D., Jafari, E., Nikbakht, H., Nasiri, B., Shamshirgaran, M., & Aminisani, N. (2019). Gender differences in health-related quality of life among patients with colorectal cancer. *Journal of Gastrointestinal Oncology*, *10*(3), 453. https://doi.org/10.21037/jgo.2019.02.04

LeBlanc, K., Heerschap, C., Martins, L., Butt, B., Wiesenfeld, S., & Woo, K. (2019). The financial impact of living in Canada with an ostomy: A cross-sectional survey. *Journal of Wound Ostomy & Continence Nursing*, *46*(6), 505-512. https://doi.org/10.1097/WON.0000000000000590

Lin, Y. (2021 May 11). *10 Reddit statistics every marketer should know in 2021.* Oberlo. https://www.oberlo.ca/blog/reddit-statistics#:~:text=Reddit%20is%20the%20most%20popular,more%20than%20130%2C000%20active%20communities

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE Publications, Inc.

Long, K. M., McDermott, F., & Meadows, G. N. (2018). Being pragmatic about healthcare complexity: Our experiences applying complexity theory and pragmatism to health services research. *BioMed Central Medicine*, *16*(1), 1-9.

https://doi.org/10.1186/s12916-018-1087-6

Lopes, A. P. A. T., & Decesaro, M. N. (2014). Adjustments experience by persons with an ostomy: An integrative review of the literature. *Ostomy Wound Management 60*(10):34-42.

Lumdubwong, A., Sirapo-ngam, Y., Arpananthikul, M., Viwatwongkasem, C., & Redeker, N. S. (2014). A comparative study of friendship therapy groups for Thais with colorectal cancer and colostomies. *Pacific Rim International Journal of Nursing Research*, *18*(2), 138-151. https://he02.tci-thaijo.org/index.php/PRIJNR/article/view/12084

Lundy, J. J., Coons, S. J., Wendel, C., Hornbrook, M. C., Herrinton, L., Grant, M., & Krouse, R. S. (2009). Exploring household income as a predictor of psychological well-being among long-term colorectal cancer survivors. *Quality of Life Research*, *18*(2), 157-161. https://doi.org/10.1007/s11136-008-9432-4

Macrae, F. A. (2022). Colorectal cancer: Epidemiology, risk factors, and protective factors. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/colorectal-cancer-epidemiology-risk-factors-and-protective-factors

Mahan, L. K., Escott-Stump, S., Raymond, J. L., & Krause, M. V. (2012). *Krause's food & the nutrition care process (13th ed.).* Elsevier/Saunders.

McDonough, M. R. (2013). A Dietitian's guide to colostomies and ileostomies. *Support Line*, *35*(3), 3-12.

Miller, L. R. (2020). Ostomy care during hospital stay for ostomy surgery and the United Ostomy Associations of America patient bill of rights: A cross-sectional study. *Journal of Wound, Ostomy and Continence Nursing*, *47*(6), 589-593. https://doi.org/10.1097/WON.0000000000000709

Mols, F., Lemmens, V., Bosscha, K., Broek, W., & Thong, M. (2014). Living with the physical and mental consequences of an ostomy: A study among 1–10-year rectal cancer survivors from the population-based PROFILES registry. *Psycho-Oncology, 23*(9), 998-1004. https://doi.org/10.1002/pon.3517

Morley, C. (2016). Development and use of the organizational framework for exploring nutrition narratives. *Journal of Critical Dietetics, 3*(2), 32-42. https://cathmorley.com/wp-content/uploads/2022/01/2016.Morley-OFFENN-JCD.pdf

Morley, C., MacLellan, D., Traviss, K., & Cividin, T. (2016). An evidence-based approach to developing the collaborative, client-centred nutrition education (3CNE) framework and practice points. *Canadian Journal of Dietetic Practice and Research*, *77*(2), 78-83. https://doi.org/10.3148/cjdpr-2015-048

Morris, A., & Leach, B. (2015). Exploring individuals' experiences of having an ileostomy and Crohn's disease and following dietary advice. *Gastrointestinal Nursing*, *13*(7), 36-41. https://doi.org/10.12968/gasn.2015.13.7.36

Mowdy, S. (1998). The role of the WOC nurse in an ostomy support group. *Journal of Wound, Ostomy and Continence Nursing 25*(1), 51-54. https://doi.org/10.1016/S1071-5754(98)90013-4

Näsvall, P., Dahlstrand, U., Löwenmark, T., Rutegård, J., Gunnarsson, U., & Strigård, K. (2017). Quality of life in patients with a permanent stoma after rectal cancer surgery. *Quality of Life Research*, *26*(1), 55-64. https://doi.org/10.1007/s11136-

016-1367-6

Newfoundland and Labrador Centre for Health Information. (2015). *Colorectal cancer.* https://www.nlchi.nl.ca/images/PDFs/Colorectal_cancer_April2015.pdf

Newfoundland and Labrador Centre for Health Information. (2018). *Ostomy procedures.* St. John’s NL.

Newfoundland and Labrador Medical Association. (2016). *Service distribution.* https://www.nlma.nl.ca/FileManager/Advocacy/docs/2016/2_NL_Health_Profile_Service_Distribution.pdf

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1-13. https://doi.org/10.1177/1609406917733847

Ostomy Canada Society. (2022). *Find a chapter/peer support group.* https://www.ostomycanada.ca/find-a-chapter-peer-support-group/

Park, A., & Conway, M. (2018). Harnessing Reddit to understand the written-communication challenges experienced by individuals with mental health disorders: Analysis of texts from mental health communities. *Journal of Medical Internet Research, 20*(4), E121. https://doi.org/10.2196/jmir.8219

Pasricha, A., Deinstadt, R., Moher, D., Killoran, A., Rourke, S. B., & Kendall, C. E. (2013). Chronic care model decision support and clinical information systems interventions for people living with HIV: A systematic review. *Journal of General Internal Medicine*, *28*(1), 127-135. https://doi.org/10.1007/s11606-012-2145-y

Pemberton, J. H. (2020). Acute colonic diverticulitis: Medical management. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/acute-colonic-diverticulitis-medical-management

Pemberton, J. H. (2021a). Acute colonic diverticulitis: Surgical management. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/acute-colonic-diverticulitis-surgical-management

Pemberton, J. H. (2021b). Colonic diverticulosis and diverticular disease: Epidemiology, risk factors, and pathogenesis. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/colonic-diverticulosis-and-diverticular-disease-epidemiology-risk-factors-and-pathogenesis

Pemberton, J. H. (2021c). Clinical manifestations and diagnosis of acute diverticulitis in adults. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/clinical-manifestations-and-diagnosis-of-acute-diverticulitis-in-adults

Peppercorn, M. A., & Cheifetz, A. S. (2021). Definitions, epidemiology, and risk factors for inflammatory bowel disease. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/definitions-epidemiology-and-risk-factors-for-inflammatory-bowel-disease

Peppercorn, M. A., & Kane, S. V. (2021a). Clinical manifestations, diagnosis, and prognosis of Crohn disease in adults. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/clinical-manifestations-diagnosis-and-prognosis-of-crohn-disease-in-adults

Peppercorn, M. A., & Kane, S. V. (2021b). Clinical manifestations, diagnosis, and prognosis of ulcerative colitis in adults. *UpToDate*. Retrieved March 14, 2022, from https://www.uptodate.com/contents/clinical-manifestations-diagnosis-and-prognosis-of-ulcerative-colitis-in-adults

Pittman, J., Nichols, T., & Rawl, S. M. (2017). Evaluation of web-based ostomy patient support resources. *Journal of Wound, Ostomy and Continence Nursing*, *44*(6), 550-556. https://doi.org/10.1097/WON.0000000000000371

Polit, D.F., & Beck, C.T. (2014). *Essentials of nursing research: Appraising evidence for nursing practice* (8th ed.). Lippincott Williams & Wilkins.

Popek, S., Grant, M., Gemmill, R., Wendel, C. S., Mohler, M. J., Rawl, S. M., ... & Krouse, R. S. (2010). Overcoming challenges: Life with an ostomy. *The American Journal of Surgery*, *200*(5), 640-645. https://doi.org/10.1016/j.amjsurg.2010.07.009

Ramirez, M., Altschuler, A., McMullen, C., Grant, M., Hornbrook, M., & Krouse, R. (2014). "I didn't feel like I was a person anymore": Realigning full adult personhood after ostomy surgery. *Medical Anthropology Quarterly*, *28*(2), 242-259. https://doi.org/10.1111/maq.12095

Reddit Inc. (2021). *Ostomy: For people with bags & those who love them.* https://www.reddit.com/r/ostomy/

Registered Nurses' Association of Ontario. (2019). *Supporting adults who anticipate or live with an ostomy.* (2nd ed.). https://rnao.ca/sites/rnao-ca/files/Ostomy_Care__Management.pdf

Regueiro, M., & Hashash, J. A. (2021). Overview of the medical management of mild (low risk) crohn disease in adults. *UpToDate*. Retrieved March 14, 2022, from https://www.uptodate.com/contents/overview-of-the-medical-management-of-mild-low-risk-crohn-disease-in-adults

Richbourg, L. (2012). Food fight: Dietary choices made by people after stoma formation. *Gastrointestinal Nursing*, *10*(4), 44-50. https://doi.org/10.12968/gasn.2012.10.4.44

Rivera, I. (2021). *Package 'RedditExtractoR'.* https://cran.r-project.org/web/packages/RedditExtractoR/RedditExtractoR.pdf

Rodriguez-Bigas, M. A., & Overman, M. J. (2022). Overview of the management of primary colon cancer. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/overview-of-the-management-of-primary-colon-cancer

Rstudio. (2018). *Why Rstudio?* https://www.rstudio.com/about

Ryan, D. P., & Willett, C. G. (2021). Treatment of anal cancer. *UpToDate.* Retrieved March 14, 2022, from https://www.uptodate.com/contents/treatment-of-anal-cancer

Sasaki, V. D. M., Teles, A. A. D. S., Silva, N. M., Russo, T. M. D. S., Pantoni, L. A., Aguiar, J. C., & Sonobe, H. M. (2021). Self-care of people with intestinal ostomy: Beyond the procedural towards rehabilitation. *Revista Brasileira de Enfermagem*, *74*(1)e20200088-8. https://doi.org/10.1590/0034-7167-2020-0088

Savard, J., & Woodgate, R. (2009). Young peoples' experience of living with ulcerative colitis and an ostomy. *Gastroenterology Nursing*, *32*(1), 33-41. https://doi.org/10.1097/SGA.0b013e3181965d40

Scardillo, J., Dunn, K. S., & Piscotty, R. (2016). Exploring the relationship between resilience and ostomy adjustment in adults with a permanent ostomy. *Journal of*

Wound, Ostomy and Continence Nursing, *43*(3), 274-279. https://doi.org/10.1097/WON.0000000000000222

Schimmelpfenning, D. P., & Mollenhauer, S. K. (2009). local ostomy support groups: Keeping the support alive. *Journal of Wound Ostomy & Continence Nursing*, *36*(3S), S32. https://doi.org/10.1097/01.WON.0000351978.68059.e9

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63-75. https://doi.org/10.3233/EFI-2004-22201

Smith, D. M., Loewenstein, G., Rozin, P., Sherriff, R. L., & Ubel, P. A. (2007). Sensitivity to disgust, stigma, and adjustment to life with a colostomy. *Journal of Research in Personality*, *41*(4), 787-803. https://doi.org/10.1016/j.jrp.2006.09.006

Sowles, S. J., McLeary, M., Optican, A., Cahn, E., Krauss, M. J., Fitzsimmons-Craft, E. E., ... & Cavazos-Rehg, P. A. (2018). A content analysis of an online pro-eating disorder community on Reddit. *Body Image*, *24*, 137-144.3. https://doi.org/10.1016/j.bodyim.2018.01.001

Statistics Canada. (2022). *Census profile, 2021 census of population.* https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/index.cfm?Lang=E

Sun, V., Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., . . . Krouse, R. S. (2013). Surviving colorectal cancer: Long-term, persistent ostomy-specific concerns and adaptations. *Journal of Wound, Ostomy, and Continence Nursing, 40*(1), 61. https://doi.org/10.1097/WON.0b013e3182750143

Taylor, B., Francis, K., and Hegney, D. (2013). *Qualitative research in the health* *sciences*. New York: Routledge.

Thorpe, G., & McArthur, M. (2017). Social adaptation following intestinal stoma formation in people living at home: A longitudinal phenomenological study. *Disability and Rehabilitation, 39*(22), 2286-2293. https://doi.org/10.1080/09638288.2016.1226396

The R Foundation. (n.d.). *What is R?* https://www.r-project.org/about.html

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388-396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van den Bos, G. A., Nijboer, C., & Sanderman, R. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology*, *9*(4), 465-478. https://doi.org/10.1348/1359107042304588

Valtolina, I. (2021, May 26). *Emptying an ostomy bag: Tips & tricks for avoiding a mess.* Farmoderm. https://farmoderm.it/en/emptying-an-ostomy-bag/

Vancouver United Ostomy Association Chapter. (2017). *A handbook for new ostomy patients (7th ed).* Ottawa Ostomy. https://ottawaostomy.ca/wp-content/uploads/2018/02/A-Handbook-for-New-Ostomy-Patients.pdf

Vonk-Klaassen, S. M., de Vocht, H. M., den Ouden, M. E., Eddes, E. H., & Schuurmans, M. J. (2016). Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: A systematic review. *Quality of Life Research*, *25*(1), 125-133. https://doi.org/10.1007/s11136-015-1050-3

Wagner, E. H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*, *1*(1), 2-4. https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.606.2262&rep=rep1&type=pdf

Weinstein RS, Holcomb MJ, Mo J, et al. An ostomy self-management telehealth intervention for cancer survivors: Technology-related findings from a randomized controlled trial. *Journal of Medical Internet Research, 23*(9), e26545. https://doi.org/10.2196/26545

Weizman, A. V., & Nguyen, G. C. (2011). Diverticular disease: Epidemiology and management. *Canadian Journal of Gastroenterology*, *25*(7), 385-389. https://doi.org/10.1155/2011/795241

Western Health. (2016). *Special assistance program.* https://westernhealth.nl.ca/home/health-topics-main/special-assistance-program/

Whiteley, I., Khatri, S., & Butler, S. (2019). Reflections on a bowel cancer support group 6 years from inception. *Journal of Stomal Therapy Australia*, *39*(3), 12-15. https://doi.org/10.33235/jsta.39.3.12-15

Wickham, H. (2021). *dplyr: A grammar of data manipulation.* https://cran.rproject.org/web/packages/dplyr/index.html

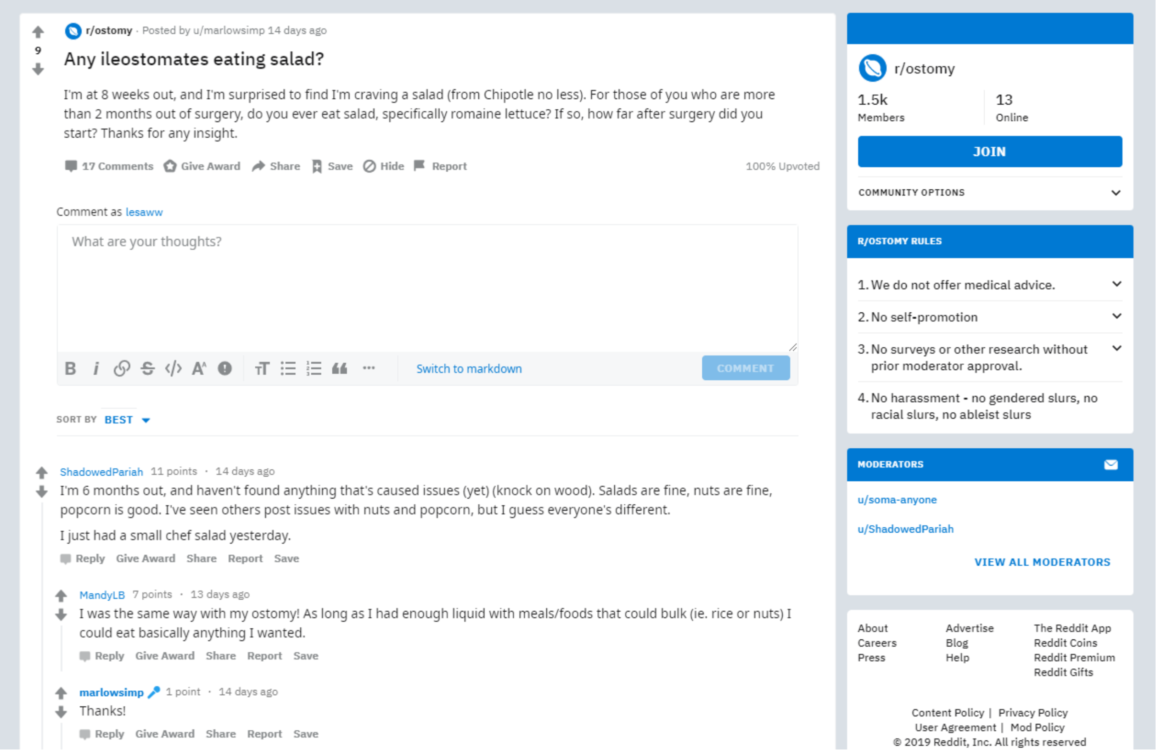
Zelga, P., Kluska, P., Zelga, M., Piasecka-Zelga, J., & Dziki, A. (2021). Patient-related factors associated with stoma and peristomal complications following fecal ostomy surgery: A scoping review. *Journal of Wound, Ostomy and Continence Nursing*, *48*(5), 415-430. https://doi.org/10.1097/WON.0000000000000796

Zhang, J. E., Wong, F. K. Y., You, L. M., Zheng, M. C., Li, Q., Zhang, B. Y., ... & Liu, J.

L. (2013). Effects of enterostomal nurse telephone follow-up on postoperative adjustment of discharged colostomy patients. *Cancer Nursing*, *36*(6), 419-428. https://doi.org/10.1097/NCC.0b013e31826fc8eb

Appendices

Appendix A: Example Thread from Reddit



r/ostomy · Posted by u/marlowsimp 14 days ago

9

Any ileostomates eating salad?

I'm at 8 weeks out, and I'm surprised to find I'm craving a salad (from Chipotle no less). For those of you who are more than 2 months out of surgery, do you ever eat salad, specifically romaine lettuce? If so, how far after surgery did you start? Thanks for any insight.

17 Comments · 100% Upvoted

Comment as lesaww

What are your thoughts?

ShadowedPariah 11 points · 14 days ago

I'm 6 months out, and haven't found anything that's caused issues (yet) (knock on wood). Salads are fine, nuts are fine, popcorn is good. I've seen others post issues with nuts and popcorn, but I guess everyone's different.

I just had a small chef salad yesterday.

MandyLB 7 points · 13 days ago

I was the same way with my ostomy! As long as I had enough liquid with meals/foods that could bulk (ie. rice or nuts) I could eat basically anything I wanted.

marlowsimp 1 point · 14 days ago

Thanks!

r/ostomy

1.5k Members · 13 Online

R/OSTOMY RULES

1. We do not offer medical advice.
2. No self-promotion
3. No surveys or other research without prior moderator approval.
4. No harassment - no gendered slurs, no racial slurs, no ableist slurs

MODERATORS

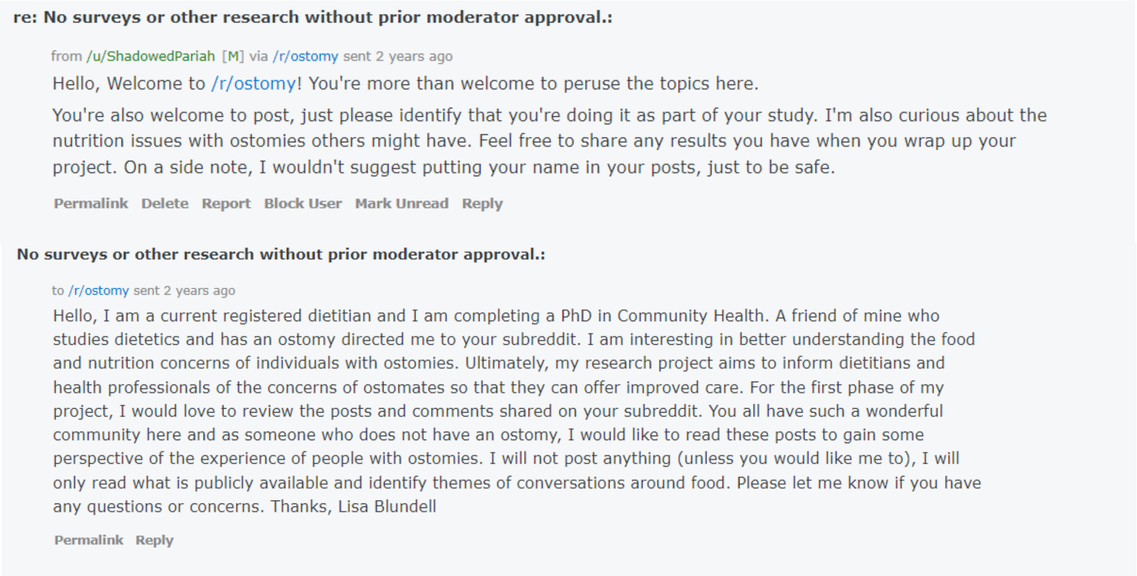
u/soma-anyone

u/ShadowedPariah

Figure A-1

Example of Threads on r/ostomy Subreddit

Appendix B: Communication with Subreddit Moderator



re: No surveys or other research without prior moderator approval.:

from /u/ShadowedPariah [M] via /r/ostomy sent 2 years ago

Hello, Welcome to /r/ostomy! You're more than welcome to peruse the topics here.

You're also welcome to post, just please identify that you're doing it as part of your study. I'm also curious about the nutrition issues with ostomies others might have. Feel free to share any results you have when you wrap up your project. On a side note, I wouldn't suggest putting your name in your posts, just to be safe.

No surveys or other research without prior moderator approval.:

to /r/ostomy sent 2 years ago

Hello, I am a current registered dietitian and I am completing a PhD in Community Health. A friend of mine who studies dietetics and has an ostomy directed me to your subreddit. I am interesting in better understanding the food and nutrition concerns of individuals with ostomies. Ultimately, my research project aims to inform dietitians and health professionals of the concerns of ostomates so that they can offer improved care. For the first phase of my project, I would love to review the posts and comments shared on your subreddit. You all have such a wonderful community here and as someone who does not have an ostomy, I would like to read these posts to gain some perspective of the experience of people with ostomies. I will not post anything (unless you would like me to), I will only read what is publicly available and identify themes of conversations around food. Please let me know if you have any questions or concerns. Thanks, Lisa Blundell

Figure B-1

Communication with Moderator of r/ostomy

Appendix C: Handout for Recruitment of People with Ostomies

EXPLORING FOOD AND NUTRITION CONCERNS OF PEOPLE WITH OSTOMIES

Research study by Memorial University PhD Student

We are researching food-related concerns of people with ostomies to improve dietetic counselling. **We are looking for people with an ostomy to participate in two 30-minute interviews to discuss food and eating.** Participants will receive $20 in gift cards.

Interested? To ask questions contact:
Lisa Blundell, RD
lisa.blundell@mun.ca/(709)864-4957

If you have questions regarding your rights as a research participant please contact the Health Research Ethics Authority at (709) 777-6974 or info@hrea.ca.

Appendix D: Demographic Questionnaire for People with Ostomies

1. What was your sex assigned at birth?
- ☐ Male
- ☐ Female
- ☐ Intersex

1. What gender do you identify as?

____

2. Please indicate your year of birth.

____

3. Please indicate the community where you currently live.

____

4. (a) What is your diagnosis that led to your ostomy?
- ☐ Ulcerative Colitis
- ☐ Crohn's Disease
- ☐ Colorectal cancer
- ☐ Other: _________________

4. (b) When were you diagnosed with this condition (month and year)?

____

6. What type of ostomy do you have?
- ☐ Ileostomy
- ☐ Colostomy
- ☐ Other: ____________
- ☐ Unsure

8. Where do you receive health care related to your ostomy? (Select all that apply):
- ☐ Eastern Health
- ☐ Central Health
- ☐ Western Health
- ☐ Labrador Grenfell Health

Appendix E: Interview Protocol for People with Ostomies

1. Can you tell me how you came to have an ostomy? When?

2. Can you describe your eating habits before being diagnosed with ______?
   - What were your favourite foods?
   - Who did you usually eat with?
   - How often would you eat out?

3. What were your eating habits like first having an ostomy?
   - Do you avoid any foods? If so, why?
   - Who do you usually eat with?
   - How often do you eat out?
   -
4. Has your eating changed at all since then? How so?
   - What role does food and nutrition currently play in self-management of your ostomy?
   - Where do you look for nutrition advice?

5. How has your ostomy changed how you think about food?
   - How has your experience affected the way you think about food and nutrition?
   - Where do you look for nutrition advice?

6. Besides eating, what were your day-to-day concerns about managing an ostomy?
   - What has it been like for you to adapt to life with an ostomy?

7. How are you currently coping with having an ostomy?
   - How confident do you feel to self-mange your ostomy in your day-to-day settings? (home, work, social outings)

8. Has having an ostomy changed how you view your body? How so?
   - Do you feel different about how you look than you did before your surgery? Over time?

9. How has your ostomy affected your relationships with family and friends?
   - Over time?

10. How has your ostomy affected your overall quality of life? How would you describe your quality of life now?

11. I'd like to ask you about the health services and support you've received. Who have you seen, and what did you discuss with them?

- Have you seen a dietitian/nurse/doctor? What did you and your dietitian/nurse/doctor discuss?
- Was there any advice that you found helpful or unhelpful?
- Were there any nutrition concerns you had that were not addressed?

12. Who else do you go to for information about living with an ostomy?
    - Do you find information online? Support groups? Friends, ostomates, family?

13. Are you still seeing a dietitian? Why or why not?
    - What types of issues do you discuss?
    - How are these visits helping you manage?
    - What other types of information would you want from the dietitian?

14. What advice do you have for dietitians and other health professionals working with people living with ostomies?

15. Is there anything else you can think of that you want to share with me about your experience?

Appendix F: Health Research Ethics Board Approval Letter for Patient Study

NEWFOUNDLAND AND LABRADOR
HREB
HEALTH RESEARCH ETHICS BOARD

Research Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure
Avenue St. John's, NL
A1B 2X5

This replaces letter dated May 25, 2020

May 26, 2020

Dear Ms Blundell:

Researcher Portal File # 20210132
Reference # 2020.061

RE: Investigating patients' experiences of adjustment to life with an ostomy and dietetic counselling

Your application was reviewed by a subcommittee under the direction of the HREB and your response was reviewed by the Chair and the following decision was rendered:

X	Approval
	Approval subject to changes
	Rejection

Ethics approval is granted for one year effective May 25, 2020. This ethics approval will be reported to the board at the next scheduled HREB meeting.

This is to confirm that the HREB reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Research proposal, approved
- Updated demographic questionnaire, approved
- Updated telephone and email scripts, approved
- Updated consent form, approved
- Interview questions and probes, approved
- Budget, approved
- Recruitment advertisement, approved

Please note the following:

- This ethics approval will lapse on May 25, 2021. It is your responsibility to ensure that the Ethics Renewal form is submitted prior to the renewal date.
- This is your ethics approval only. Organizational approval may also be required. It is your responsibility to seek the necessary organizational approvals.
- Modifications of the study are not permitted without prior approval from the HREB. Request for modification to the study must be outlined on the relevant Event Form available on the Researcher Portal website.
- Though this research has received HREB approval, you are responsible for the ethical conduct of this research.
- If you have any questions please contact info@hrea.ca or 709 777 6974.

The HREB operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), ICH Guidance E6: Good Clinical Practice Guidelines (GCP), the Health Research Ethics Authority Act (HREA Act) and applicable laws and regulations.

We wish you every success with your study.

Sincerely,

The image part with relationship ID rId156 was not found in the file.

Dr Fern Brunger, Chairperson
Health Research Ethics Board

You Have Received Ethics Approval, Now What?: HREB Reporting Requirements

Once a study has received ethics approval from the Health Research Ethics Board (HREB), there are still associated reporting requirements. In the conduct of approved research researchers are required to report to the HREB, in a timely manner, proposed changes from approved research that affect participants at any stage of the process. This includes, but is not limited to, changes to the consent form, changes to the tasks or interventions involved in the research, or changes to measures to protect privacy and confidentiality.

Any substantive change to the research should not be implemented prior to documented approval by the HREB, except when necessary to eliminate an immediate risk(s) to the participants. Below are examples of post approval documentation that must be submitted to the HREB:

Amendments

Any proposed change in the conduct of a study must be submitted to the HREB, and approved, before the change may be implemented. Such changes might include modification of recruitment procedures, inclusion or exclusion criteria, revised sample size, addition or deletion of study sites, changes to an intervention, consent forms, questionnaires or scripts, etc. If there are changes in project team members or changes to funding source(s)/sponsor(s), there are specific forms to complete to report this to the HREB.

Adverse Events

Serious and unanticipated adverse events that occur within Newfoundland and Labrador are required to be reported to the HREB. Such events may occur in both clinical trials and in other types of research, e.g. collapse during a rehabilitation program, emotional breakdown requiring follow up care during an interview, or breach of privacy during correspondence. Serious adverse events that are fatal or life-threatening are required to be reported to the HREB as soon as the research team is aware of the event.

Protocol Deviations

Deviations from an approved study protocol must be reported to the HREB. Changes that eliminate immediate hazards to participants do not require prior approval, but must be reported soon as reasonably possible.

Safety Reports

Safety reports providing information on all serious adverse events (SAEs) occurring in a clinical trial must be provided by the sponsor to the HREB, normally on a three or six monthly basis (i.e. in accordance with the specified reporting timelines that were outlined in the approved ethics application).

Investigator Brochure (IB) and Product Monograph (PM)

Throughout the course of a clinical trial, changes may be implemented to study documents. All revisions to approved study documents must be submitted to the HREB to ensure the record is up to date. If the revisions include new risk or safety information there may be a requirement to notify research participants.

Ethics Renewal/Study Closure

Ethics approval lasts for one year. Ethics renewal is required annually, on the anniversary of the date of the HREB notification of approval. Once data collection is no longer ongoing, a study closure form is required to be submitted to the HREB for the study to remain active or to be closed in good standing.

Appendix G: Demographic Questionnaire for HCPs and Support Group Leaders

1. What gender do you identify as?

____

2. How long in have you been in your profession/role?

____

3. How many years of experience do you have caring/providing support for people with ostomies?

____

4. Where do you provide health care for people with an ostomy? (Select all that apply).

☐ Eastern Health region
☐ Central Health region
☐ Western Health region
☐ Labrador Grenfell Health region

Appendix H: Interview Protocol for HCPs and Support Group Leaders

*[*Note: Wording will be slightly modified for the type of interviewee. (i.e. for support group leaders, we will refer to patients as 'peers')]*

16. To start, can you describe your role in providing care to people with ostomies?
    - What patient population do you typically care for?
    - What type of topics do you usually cover with a patient?
    - Who do you regularly work with? (E.g. nurses, dietitians, etc.)

17. In your opinion, what does good patient care/support look like for people with ostomies?
    - How does this evolve or change over time?
    - How do you incorporate the patient's goals?

18. What types of support do you provide to patients to help with:
    - nutrition and food-related concerns?
        i. Is there any specific advice or sources of information you provide?
    - physical management?
        i. Is there any specific advice or sources of information you provide?
    - psychosocial adaptation to an ostomy?
        i. Is there any specific advice or sources of information you provide?

[For dietitians only:]

19. What is your experience providing dietetic counselling to patients with ostomies?
    - What do your patients usually ask you about?
    - What do you typically discuss with patients who have recently had surgery?
    - How does this change over time?

20. How do you work with other members of the health care team to ensure patients' nutrition concerns are addressed?

21. Do you work with community partners to provide nutrition guidance to community groups, such as Ostomy Canada support groups? If yes, how so?

[All:]

22. Are there any barriers or gaps that exist which prevent or hinder you from providing good patient care/support to people with ostomies?

23. How could we improve care/support for patients with ostomies?

24. Is there anything else you would like to add?

Appendix I: Health Research Ethics Board Approval Letter for Provider Study

Research Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure
Avenue St. John's, NL
A1B 2X5

May 25, 2020

Dear Ms Blundell:

Researcher Portal File # 20210133
Reference # 2020.060

RE: Examining diet-related health care for people living with an ostomy

Your application was reviewed by a subcommittee under the direction of the HREB and your response was reviewed by the Chair and the following decision was rendered:

X	Approval
	Approval subject to changes
	Rejection

Ethics approval is granted for one year effective May 25, 2020. This ethics approval will be reported to the board at the next scheduled HREB meeting.

Please note this approval is deferred until the public health crisis related to COVID-19 has abated. No new studies involving face-to-face contact may be initiated at this time. Once this crisis has abated you will receive a communication with a revised letter. Do not begin any recruitment, consent processes, or study interventions until you receive your revised letter. If

you have any questions please contact the Ethics Officer at ethicsofficer@hrea.ca. Thank you for your patience.

This is to confirm that the HREB reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Research proposal, approved
- Updated telephone and email scripts, approved
- Revised consent form, approved
- Interview protocol, approved
- Demographic questionnaire, approved

Please note the following:

- This ethics approval will lapse on May 25, 2021. It is your responsibility to ensure that the Ethics Renewal form is submitted prior to the renewal date.
- This is your ethics approval only. Organizational approval may also be required. It is your responsibility to seek the necessary organizational approvals.
- Modifications of the study are not permitted without prior approval from the HREB. Request for modification to the study must be outlined on the relevant Event Form available on the Researcher Portal website.
- Though this research has received HREB approval, you are responsible for the ethical conduct of this research.
- If you have any questions please contact info@hrea.ca or 709 777 6974.

The HREB operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), ICH Guidance E6: Good Clinical Practice Guidelines (GCP), the Health Research Ethics Authority Act (HREA Act) and applicable laws and regulations.

We wish you every success with your study.

Sincerely,

Dr Fern Brunger, Chairperson
Health Research Ethics Board

You Have Received Ethics Approval, Now What?: HREB Reporting Requirements

Once a study has received ethics approval from the Health Research Ethics Board (HREB), there are still associated reporting requirements. In the conduct of approved research researchers are required to report to the HREB, in a timely manner, proposed changes from approved research that affect participants at any stage of the process. This includes, but is not limited to, changes to the consent form, changes to the tasks or interventions involved in the research, or changes to measures to protect privacy and confidentiality.

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Amendments

Any proposed change in the conduct of a study must be submitted to the HREB, and approved, before the change may be implemented. Such changes might include modification of recruitment procedures, inclusion or exclusion criteria, revised sample size, addition or deletion of study sites, changes to an intervention, consent forms, questionnaires or scripts, etc. If there are changes in project team members or changes to funding source(s)/sponsor(s), there are specific forms to complete to report this to the HREB.

Adverse Events

Serious and unanticipated adverse events that occur within Newfoundland and Labrador are required to be reported to the HREB. Such events may occur in both clinical trials and in other types of research, e.g. collapse during a rehabilitation program, emotional breakdown requiring follow up care during an interview, or breach of privacy during correspondence. Serious adverse events that are fatal or life-threatening are required to be reported to the HREB as soon as the research team is aware of the event.

Protocol Deviations

Deviations from an approved study protocol must be reported to the HREB. Changes that eliminate immediate hazards to participants do not require prior approval, but must be reported soon as reasonably possible.

Safety Reports

Safety reports providing information on all serious adverse events (SAEs) occurring in a clinical trial must be provided by the sponsor to the HREB, normally on a three or six monthly basis (i.e. in accordance with the specified reporting timelines that were outlined in the approved ethics application).

Investigator Brochure (IB) and Product Monograph (PM)

Throughout the course of a clinical trial, changes may be implemented to study documents. All revisions to approved study documents must be submitted to the HREB to ensure the record is up to date. If the revisions include new risk or safety information there may be a requirement to notify research participants.

Ethics Renewal/Study Closure

Ethics approval lasts for one year. Ethics renewal is required annually, on the anniversary of the date of the HREB notification of approval. Once data collection is no longer ongoing, a study closure form is required to be submitted to the HREB for the study to remain active or to be closed in good standing.

Appendix J: Map of Regional Health Authorities

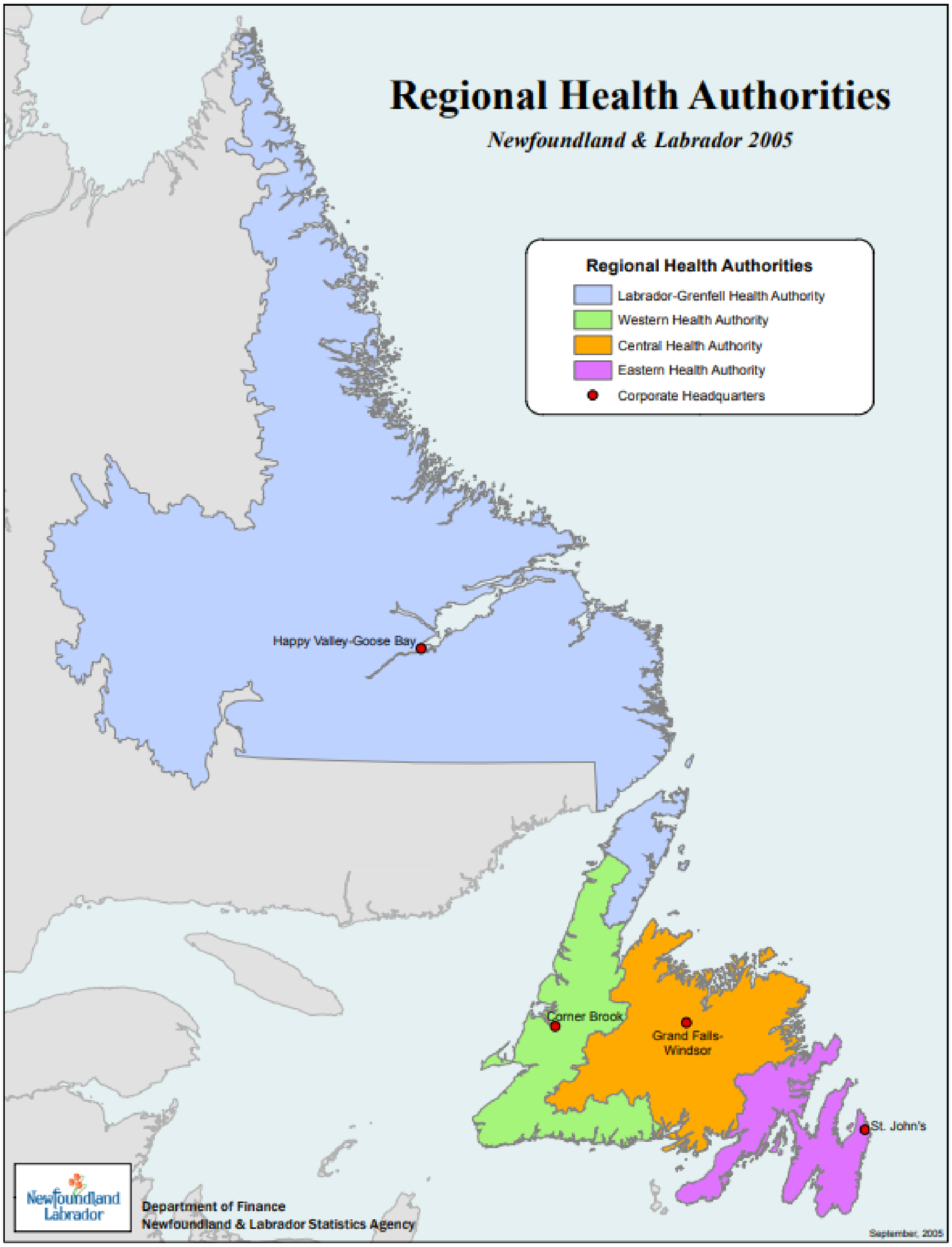

Figure J-1

Map of Regional Health Authorities in NL

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