

Transitioning with an Ostomy: The Experience of Patients
with Cancer following Hospital Discharge

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Abstract

The study aim was to describe the lived experience of patients with an ostomy due to cancer following hospital discharge, using a Heideggerian phenomenological lens. Colaizzi's (1978) process guided a thematic analysis of nine unstructured interviews.

The overall essence of patients' transition experience was *Adjusting to a New Way of Living*. Four major themes emerged, *Some Things are Different*, *Always on my Mind*, *Moving Towards Independence*, and *I'm Not Alone*. Results suggest that the transition involves: adjusting to the ostomy and cancer; financial implications; changes in self, physical being, lifestyle, and social aspects of life; and psychological acceptance and preparation for the unexpected. Home care nurses and patients' support network facilitated meeting their comprehensive care needs; while cancer treatments, the role of the significant other in the loss of privacy, funding inconsistencies, and temporary ostomy status were barriers. Patients need a comprehensive care approach to better facilitate the transition process.

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Chapter 1 – Introduction

In North America, approximately 70, 000 patients undergo ostomy surgery each year (United Ostomy Association of Canada, 2009). An *ostomy* is a surgical diversion of either the gastroenterological tract or urinary tract through the abdomen for the elimination of either stool or urine from a stoma, or opening. The Oryx Group, a private research firm, estimated that between 1999 and 2000, 13, 000 ostomy surgeries were performed in Canada; 55% were colostomies, 31% ileostomies, and 14% urostomies (cited by Registered Nurses' Association of Ontario [RNAO], 2009).

An ostomy may be created at any age; be permanent or temporary; and be due to several diseases, including cancer, inflammatory bowel disease, bowel ischemia, diverticulitis, necrotizing enterocolitis, congenital anomalies and conditions (e.g., hirschsprung disease); and other circumstances such as obstruction, perforation, and trauma (Avunduk, 2008; RNAO, 2009; Steele, 2006). Following ostomy surgery, individuals may experience lifestyle changes (e.g., bowel routine; body image and sexuality; social, physical, and leisure activities) which often affect their overall wellbeing and adjustment (Annells, 2006; Borwell, 1997; Brown & Randle, 2005; Ito et al., 2012; Persson & Hellström, 2002; Pittman, Kozell, & Gray, 2009; Piwonka & Merino, 1999; RNAO, 2009; Simmons, Smith, Bobb, & Liles, 2007). For individuals who undergo ostomy surgery due to cancer however, there is the additional burden of dealing with a potentially life threatening disease. Patients with cancer experience a unique disease journey and set of needs in comparison to patients without cancer (Fitch, 2008a; Fitch, 2008b; Fitch & Steele, 2008), thus, patients with an ostomy due to cancer are a unique group of patients because their care needs relate to both the ostomy and cancer.

According to the RNAO's (2009) clinical guidelines on ostomy care and management, the Oryx Group estimates that 36% of ostomy surgeries in Canada are due to colorectal cancer (as cited by RNAO, 2009).

In Canada, 23, 300 new colorectal cancer cases were expected in 2012, making it the third most common cancer expected to be diagnosed in both men and women (13% of all cancers) (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). As well, in 2012, colorectal cancer was expected to account for 9, 200 deaths (12% of all cancer deaths), and fifty per cent of all new cases were expected to occur among those 70 years and older (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). In 2012, the highest incidence rates for both males and females were expected in Newfoundland and Labrador, the lowest in British Columbia, and 4, 800 males and 3, 900 females in Ontario (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012).

There is a paucity of research on the specific care needs of patients with an ostomy as they transition from hospital to home. A search through the literature related to the transition experience of patients with an ostomy revealed that few studies involving patients in the Canadian health care system have been conducted (e.g., Baich, Wilson, & Cummings, 2010; Erwin-Toth, Thompson, & Davis, 2012). One of the few known Canadian studies examined patients' view on how colorectal cancer affected them psychosocially, where about half of participants had an ostomy, and the time between diagnosis and interview was 6 months to 7 years (Sahay, Gray, & Fitch, 2000).

Clinical guidelines on ostomy care recommend that patients with an ostomy and their families be discharged from hospital with home care support (RNAO, 2009). Health

care is provincially legislated across Canada. In Ontario, the Community Care Access Centres coordinate access to home care support after hospital discharge, acting as a contractor to local community agencies that provide the services warranted (Community Care Access Centre, n.d.; Forbes & Edge, 2009). Timely access to home care services however, is challenged by the limited supply of health care workers (The Canadian Home Care Association, 2011) and funding (Armstrong-Stassen & Cameron, 2005; Forbes & Edge, 2009; Stajduhar et al., 2011). To address community support, ostomy telenursing visits have been utilized in the United States (Bohnenkamp, McDonald, Lopez, Krupinski, & Blackett, 2004), and ostomy telephone nursing services in China (Zhang, Wong, You, & Zheng, 2012). Community resources available in Canada include the internet, support groups, resource centres, and ostomy supply companies (RNAO, 2009), but their availability and accessibility is dependent on local and personal resources (e.g., internet access).

In summary, research on the specific care needs of patients with an ostomy who are transitioning following hospital discharge is limited. Thus, the purpose of this study was to describe the *lived experience* of patients with an ostomy due to cancer following hospital discharge. Such a study therefore explored the transition experience of patients with an ostomy due to cancer in the home setting and contributed to the following objectives within a Canadian context:

1. To describe the experience and care needs of these patients.
2. To describe facilitators to meeting the care needs of these patients.
3. To describe barriers to meeting the care needs of these patients.

Chapter 2 – Literature Review

This chapter describes the current state of knowledge related to the transition experience of patients with an ostomy, beginning with a description of the literature search procedure. Conceptualization of a transition and its main elements (i.e., the critical event, movement, coping and adaptation, and the role of nurses), and an explanation of how the Supportive Care Framework (SCF) (Fitch, 2008a; Fitch, 2008b) is appropriate and beneficial for examining a transition will follow. The seven need domains of the SCF (i.e., physical, psychological, emotional, spiritual, social, practical, and informational) (Fitch, 2008a; Fitch, 2008b) will be used to organize a summary on the current understanding of the experiences of patients with an ostomy, and evidence-based nursing interventions to support patients' adjustment to an ostomy. As a result, gaps in the current literature and areas requiring further research will be identified.

Literature Search Procedure

In planning the study, a search was conducted in the CINAHL database using the terms *ostomy* and *education* for articles published between 1981 and 2009 (see Appendix A for the Literature Search Procedure). To ensure thoroughness, searches of the keywords *ostomy*, *ostomate*, *ostomies*, *colostomy*, and *ileostomy* (each separated by the word *or*) with different combinations of the keywords *education*, *patient*, *patient education*, *cancer*, and *transition or coping*, using the word *and* were also conducted. Limits included peer reviewed articles on adults, published in English. Similar searches were conducted through the Ovid Medline(R), Journals@Ovid, and PsychINFO databases (see Appendix A). Reference lists of included articles were also reviewed. The search was updated in 2012 with some new terms added based on the original

search (see Appendix A). Included articles were clinical guidelines, research studies using any design, and expert recommended articles. Excluded were non-adult and non-fecal ostomy related articles (this study focused on adults with a fecal ostomy), abstracts, editorials, and commentaries.

Transitions

The experience following hospital discharge is a significant period of transition in the care and management of patients with an ostomy, and is influenced by the health care system and availability of resources. To examine the significance of this experience, the following section explains the importance of transitions and includes a description of how transitions and the main elements of a transition are conceptualized (namely, the critical event, movement, coping and adaptation, and the role of nurses).

The majority of ostomy care occurs following hospital discharge, when patients may be experiencing the most challenges (Carlsson, Berndtsson, Hallén, Lindholm, & Persson, 2010; Ito et al., 2012; Marquis, Marrel, & Jambon, 2003; Pittman et al., 2009; Piwonka & Merino, 1999; RNAO, 2009) and when immediate healthcare professional support is generally limited. The Canadian home care sector has experienced increasing growth over the last four decades due to increasing demands to extend the continuum of patient care into this sector (The Canadian Home Care Association, 2011). Enterostomal (ET) nurses (may also be referred to as ostomy nurses or as wound, ostomy, and continence [WOC] nurses outside of Canada) are nurses specially trained to help people with ostomies, wounds, and continence issues (Baxter, 2000). They have been proven to help patients transition to life with an ostomy (Haugen, Bliss, & Savik, 2006; Marquis et al., 2003; Richbourg, Thorpe, & Rapp, 2007). However, their

presence in the home care sector is rare in Canada (Baich et al., 2010; St-Cyr, 2002). Hence, there is a need to understand better how to support patients with an ostomy following hospital discharge during their transition to life with an ostomy due to cancer within a Canadian context.

Murphy (1990) discusses two key points of view to understanding transitions. The first perspective takes an *evolutionary* view, focusing on the context in which a significant life event occurs and the course of change and integration of this event into one's life. The second perspective focuses on the *consequence* of a critical event that disrupts the stability between two points in time, thereby placing the emphasis on life before and after the critical event. Regardless of the perspective, an individual's response to the transition is complex and may be impacted by multiple factors. The first perspective inspired the research question for this study because of its focus on the *experience* of a transition.

Understanding the concept of transitions can be challenging due to its multidimensionality and complexity. For instance, transitions can be based on human development and maturation, altered or unexpected situations, wellness and disease, life changes or achievement of life milestones, passages of importance, alterations in role function, or organization related changes (Meleis, 2007; Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Murphy, 1990; Selder, 1989). Different types of transitions may also occur simultaneously (Meleis, 2007; Meleis et al., 2000; Schumacher & Meleis, 1994). Elements from Selder's *Life Transitions Theory* (1989) and Meleis' (2007) *Transitions: A Middle-Range Theory*, conceptualize a *transition* as a process triggered by a *critical event* that causes an individual to undergo a one-

directional *movement* from a *known (or present) reality* to a *permanently altered (or new) reality*, where during the movement the individual experiences an uncontrollable state of uncertainty and loss of normalcy. As the individual gradually moves towards fully accepting the altered reality, an increasing sense of control, certainty, and normalcy is experienced, signifying the progression of a *healthy transition*. Healthcare professionals such as nurses have an instrumental role in transitions. The *role of nurses* is to assist patients in achieving a healthy transition through *nursing interventions* that facilitate *copmg and adaptation* (Meleis, 1975; Meleis, 2007; Meleis et al., 2000; Meleis & Trangenstein, 1994; Murphy, 1990; Schumacher & Meleis, 1994). For the purposes of this study, a transition is characterized by a) a critical event that triggers a one-directional movement, where an individual moves from the known reality to the permanently altered (new) reality; b) the patient's ability to cope and adapt to the new reality; and c) the role of nurses as facilitators of a healthy transition throughout the patient's transition experience. The following sections define and discuss the main elements of a transition; the critical event, movement, coping and adaptation, and the role of nurses.

Critical event. A *critical event* refers to a situation or occurrence that triggers the transition (Meleis, 2007; Meleis et al., 2000; Meleis & Trangenstein, 1994; Neil & Barrell, 1998; Selder, 1989). For the purposes of this study, it is the moment that the patient is faced with the inevitability of undergoing ostomy surgery (be it planned or unplanned).

Movement. *Movement* within a transition refers to the one-directional process of change and adjustment that the patient undergoes following a critical event. It is during this process that the patient moves from the known reality to the permanently altered

new reality (Meleis, 2007; Meleis et al., 2000; Meleis & Trangenstein, 1994; Neil & Barrell, 1998; Selder, 1989). Transitions are one-directional because the critical event has permanently altered the known reality (Selder, 1989). For example, one cannot stop advancing towards adulthood and remain an adolescent, nor can one revert back to being a child simply because one did not want to accept the inevitability of ageing. Consequently, for the purposes of this study, the *known reality* is the patient's life before an ostomy, while the *altered reality* is the patient's life with an ostomy. Patients may either progress or struggle through the movement as they adjust to the altered reality. When they fully accept their altered reality and have an overall feeling of wellbeing, they are described as having positively adjusted to the critical event, or having achieved a healthy transition (Meleis, 2007; Meleis & Trangenstein, 1994; Neil & Barrell, 1998; Schumacher & Meleis, 1994; Selder, 1989). For the purposes of this study, a *healthy transition* refers to the patient's positive adjustment to ostomy surgery, in which the patient accepts life with an ostomy and experiences an overall feeling of wellbeing.

Coping and adaptation. The progression of the transition (or movement) is dependent on the patient's ability to adjust, or cope with and adapt to the changed reality. Based on work by Fitch (2008a; 2008b), *coping and adaptation* are dynamic processes, constantly changing over time, and for the purposes of this study, refer to the strategies a patient exercises to manage the consequences of undergoing ostomy surgery and the emotional distress it entails so that a positive adjustment may be achieved, or what is referred to in this study as a healthy transition. Patients may employ strategies that are problem-focused to manage or change the critical event, or feeling-focused strategies that attempt to manage the emotional distress resulting from

the critical event, where the type of strategy used is dependent on their appraisal of threat to their wellbeing (Fitch, 2008a; Fitch, 2008b). Hence, the emotional distress that follows is a consequence of both their threat appraisal and ability to reduce that threat. However, patients may not be cognisant of the appraisal, which is influenced by their level of knowledge, life experiences, perception of self, personal needs, mind-set, outlook on life and future goals, and cultural background (Fitch, 2008a; Fitch, 2008b).

Role of nurses. Healthcare professionals such as nurses are able to implement interventions that facilitate coping and adaptation to help patients achieve a healthy transition (Meleis, 1975; Meleis, 2007; Meleis et al., 2000; Meleis & Trangenstein, 1994; Murphy, 1990; Schumacher & Meleis, 1994). For the purposes of this study, the *role of nurses* in a transition is to implement nursing interventions that facilitate a patient's healthy transition. *Nursing interventions* are the approaches or strategies used by a nurse, or a team consisting of a nurse and other healthcare professionals, to put a plan of care into action, so that a patient's supportive care needs are addressed, and goals and projected outcomes are attained. Nursing interventions aim to help patients cope and adapt to the critical event and the emotional distress it entails. Nurses who understand transitions are able to assess for potential problems and use appropriate nursing interventions such as patient educational strategies to help individuals cope with and adapt to their altered reality, thus preventing negative patient outcomes and a poor transition (Meleis, 1975; Meleis, 2007; Meleis et al., 2000; Meleis & Trangenstein, 1994; Murphy, 1990; Neil & Barrell, 1998; Schumacher & Meleis, 1994).

The Supportive Care Framework (SCF)

According to the SCF, holistic care involves addressing seven need domains of a patient; namely *physical, psychological, emotional, spiritual, social, practical, and informational* (Fitch, 2008a; Fitch, 2008b). The SCF describes the cancer journey of patients and their families, which includes *pre-diagnosis, diagnosis, treatment, survivorship, recurrence, palliation, and bereavement*, and recognizes that holistic care needs differ among patients and change over the course of this journey, as does the character and level of influence of these needs on the patient (Fitch, 2008a; Fitch, 2008b). The SCF focuses on caring for a patient diagnosed with cancer over a period of time (although it is not considered to be a formal transition theory). The emphasis on care over an extended time suggests that the SCF supports the examination of transitions in this study. Both the journey of cancer and ostomy surgery demonstrate the three characteristics of a transition outlined within this study because a) both a cancer diagnosis and ostomy surgery, whether or not due to cancer, may be viewed as a critical event because time spent living with either can never be erased; b) both cancer and an ostomy require coping and adaptation to a new life (i.e., a life threatening disease; a new bowel routine); and c) nurses are fundamental to a patient's life following a cancer diagnosis, as well as ostomy surgery. Thus, the SCF is useful in organizing a review of the current literature on patients who may be in the midst of transitioning to life with an ostomy using the seven need domains (physical, psychological, emotional, spiritual, social, practical, and informational) (Fitch, 2008a; Fitch, 2008b). A presentation of the literature on patients' experiences with an ostomy and suggested nursing interventions to support their adjustment to an ostomy follows.

Physical needs. Physical supportive care needs refer to the necessity “for physical comfort and freedom from pain, optimum nutrition, [and] ability to carry out one’s usual day-to-day functions (i.e., activities of daily living),” (Fitch, 2008b, p. 18) and for the purposes of this study, include support for changes in bowel routine (e.g., maintaining peristomal skin integrity; changing and maintaining the ostomy appliance).

Peristomal skin integrity may influence patients’ adjustment to life with an ostomy. A literature review on peristomal allergic contact dermatitis revealed that it is a common complication for patients with an ostomy that affects their quality of life and surgical recovery (Agarwal & Ehrlich, 2010). Furthermore, peristomal dermatitis decreases the adhesive ability of ostomy equipment, resulting in improper sealing and further skin irritation, increased potential for ostomy equipment failure (e.g., leaks and odour), infection, pain, negative psychosocial effects (e.g., poor sense of worth, humiliation, poor socialization, poor mental health), and increased costs due to needed adjustments in ostomy supplies to prevent equipment failure and extra ostomy appliance changes (Agarwal & Ehrlich, 2010). Proper ostomy appliance system management is therefore critical to prevent poor peristomal skin integrity (Agarwal & Ehrlich, 2010; Boarini, 1985; ConvaTec, 2007; McMullen et al., 2011; Piras & Hurley, 2011; Ratliff, 2010). This is particularly important for patients who are undergoing cancer treatments because of the increased risk for skin breakdown from side-effects of treatment including diarrhea and immunosuppression (Gibson & Keefe, 2006; Grenon & Chan, 2009; Leung, 2011), and changes in the integumentary and vascular systems (Boarini, 1985; ConvaTec, 2007).

Because of the negative impact on patients who experience stomal or peristomal complications, there is considerable focus in the literature on patients' physical care needs compared to nonphysical care needs. There are numerous overviews of preoperative and postoperative care, and task oriented step-by-step protocols which focus on the physical health of the ostomy (e.g., K. B. Alterescu, 1985; V. Alterescu, 1985; Boarini, 1985; Bryant & Fleischer, 2000; Cronin, 2005; Doering & La Mountain, 1984; Erwin-Toth, 2001; Piras & Hurley, 2011; Smith, 1985; Tolch, 1997). However, despite evidence that patients who have confidence in managing their ostomy appliance positively adjust to their ostomy (Marquis et al., 2003; Piwonka & Merino, 1999; Simmons et al., 2007), challenges with ostomy appliance management remain (Annells, 2006; Lynch, Hawkes, Steginga, Leggett, & Aitken, 2008; Persson & Hellström, 2002; Zhang et al., 2012).

Short postoperative hospitalizations challenge nurses' ability to assess, educate, evaluate, and reinforce patients' knowledge and skills on ostomy appliance management while in hospital (RNAO, 2009; St-Cyr, 2002). Lack of critical knowledge can potentially lead to post-discharge complications in the community. For example, North American studies have reported peristomal skin conditions in patients in the community ranging from 47% (of n = 89) (Ratliff, 2010) to 61% (of n = 733) (Erwin-Toth et al., 2012), with the latter study reporting that approximately one-third of participants failed to recognize the skin condition (e.g., infection-related peristomal skin disorder, allergic contact dermatitis). International studies have reported similar findings in their community patients. A Danish study reported that 45% of their participants (n = 202) had a peristomal skin disorder, where at least 10% were severe, requiring immediate

medical attention with a potentially compromised ostomy appliance system (skin disorders were classified as mild or slight skin changes, moderate or definite skin changes such as ulcers, and severe) (Herlufsen et al., 2006). However, of participants diagnosed with a skin disorder, 67%, 41%, and 56% did not recognize that they had a mild, moderate, or severe skin disorder respectively, and more than 80% of those with a skin disorder did not seek professional help. Researchers attributed this behaviour to people failing to recognize the skin disorder, and possible lack of association with an appropriate clinic or healthcare professional. Thus, there is concern over whether or not physical care needs are being met effectively.

Assistance with ostomy care has been shown to address the physical care needs of patients with an ostomy. Compared to participants who managed their own ostomy, those who had assistance with ostomy care from spouses had better peristomal skin integrity and fewer challenges with treating problems (McMullen et al, 2011).

Interventions that specifically address physical care needs are limited. The RNAO's (2009) clinical guidelines on ostomy care and management recommend preparing patients and families with a minimum set of skills specific to their care needs. However, the clinical guidelines (RNAO, 2009) acknowledge that no literature exists on the nature of required skills. Although the clinical guidelines also recommend performing stomal and peristomal skin assessments shortly after surgery and with each appliance change using a tool to assess specific complications, no standardized tool exists. The clinical guidelines also recommend identifying complication risk factors, and educating patients and families to recognize complications. Nonetheless, more research is required to develop effective interventions specific to physical care needs.

Psychological needs. Psychological supportive care needs pertain to “the ability to cope with the illness experience and its consequences [e.g., lifestyle changes, sexuality problems], including the need for optimal personal control and the need to experience positive self-esteem” (Fitch, 2008b, p. 19). During transitions, past coping strategies may become ineffective because the added distress of illness often compromises people’s ability to meet their own needs (Fitch, 2008a; Fitch, 2008b; Meleis, 2007).

Following hospital discharge, patients with an ostomy may experience reduced pleasure in activities (Richbourg et al., 2007). An ostomy may elicit negative psychological experiences such as uncertainty and discomfort due to the loss of continence control, increased attention to and insecurity about ostomy output, and changes in body image, sexuality, and intimacy (Annells, 2006; Beaver et al., 2010; Borwell, 1997; Brown & Randle, 2005; Grant et al., 2011; Haugen et al., 2006; Honkala & Berterö, 2009; Li, Rew, & Hwang, 2012; Mitchell et al., 2007; Persson & Hellström, 2002; RNAO, 2009; Richbourg et al., 2007).

Patients must therefore cope with and adapt to their altered reality. Factors such as level of independence in ostomy management, psychological support for body image changes, social interaction and support, and acceptance of the stoma have been shown to affect adjustment to life with an ostomy in both Chilean (Piwonka & Merino, 1999) and British patients (Simmons et al., 2007). Decreased acceptance of disability among patients with colorectal cancer in Northern Taiwan was associated with having an ostomy, shorter duration of cancer disease, Dukes C1 stage or greater, and less education (Chao, Tsai, Livneh, Lee, & Hsieh, 2010). Dukes is a staging classification

system for colorectal cancer and includes four major stages, beginning with stage A through to stage D. Stage C refers to tumour invasion of the bowel musculature and nodal metastases (Huether, 2006). Studies on American patients have reported that females with an ostomy due to colorectal cancer have reported more coping and adjustment difficulties compared to males (Grant et al., 2011). In another study, when compared to matched controls (rectal cancer survivors who did not require an ostomy), females with an ostomy due to rectal cancer were shown to have poorer overall health-related quality of life scores and psychological wellbeing, while similar findings were not found between male cases and matched controls (Krouse et al., 2009). In one of the few Canadian studies related to the transition experience of patients with an ostomy, a qualitative descriptive study examining the views of 20 patients with colorectal cancer reported that in general, participants were content with their treatment and had a rather positive outlook on their experience (Sahay et al., 2000). However, the study focused on patients' perspectives of colorectal cancer and not specifically on their ostomy (11 out of 20 participants had an ostomy). Furthermore, although the time elapsed since colorectal cancer diagnosis was reported (between six months to seven years), the time elapsed since hospital discharge following ostomy surgery was not indicated. Thus, more research on the psychological care needs of patients with an ostomy due to cancer is needed because current evidence is unclear on how cancer disease affects adjustment to life with an ostomy during the transition period following hospital discharge.

Nurses are able to assist patients with their psychological care needs by teaching them effective coping strategies, and providing regular assessment and follow-up. Based on a systematic review of the literature, the RNAO's (2009) clinical guidelines on

ostomy care and management recommend helping patients deal with the loss of personal control soon after ostomy surgery. The recommendation suggests teaching patients to use coping strategies that facilitate their independence in ostomy management and restore faith in their abilities, allowing them to regain a “sense of normalcy” (RNAO, 2009, p. 22). The clinical guidelines also recommend regular assessment and follow-up with an ET nurse for at least one year after ostomy surgery to reduce psychological suffering, offer support, increase quality of life, and avoid the development of postoperative complications. For example, The Permission Granting-Limited Information-Specific Suggestions-Intensive Therapy (PLISSIT) Model is an effective assessment tool and intervention to help patients cope with sexual concerns. The model encourages patients to openly discuss their sexual concerns with healthcare professionals (Junkin & Beitz, 2005; Smith & Babaian, 1992; Weerakoon, 2001) such as ET nurses. It has been found to help decrease sexual dysfunctions in Turkish patients with an ostomy (Ayaz & Kubilay, 2009), but no known studies have examined its effectiveness in Canadian patients with an ostomy. More evaluation of interventions that address psychological care needs is necessary.

Emotional needs. Emotional supportive care needs involve the necessity “for a sense of comfort, belonging, understanding and reassurance in times of stress and upset” (Fitch, 2008b, p. 9). Transitions may evoke feelings of uncertainty (Meleis, 2007; Neil & Barrell, 1998; Selder, 1989), which may be manifested by insecurity, fear, and worry, and result in emotional distress. Emotional distress may hinder the ability and confidence of patients with an ostomy to return to work or participate in activities such as sports, and social and leisure activities (Annells, 2006; Persson & Hellström, 2002).

Following ostomy surgery, patients may experience increased depression and anxiety (Richbourg et al., 2007).

For patients with cancer, keeping a positive outlook on life can be further challenged because of the uncertainty of death. For example, the concerns and health-related quality of life of Swedish patients (N = 57) were assessed just before undergoing ostomy surgery for rectal cancer, and at one, three, and six months postoperatively using the Rating Form of Inflammatory Bowel Disease Patient Concerns and the 36-Item Short Form Health Survey version 2.0 (Carlsson et al., 2010). Findings included concerns over developing cancer and disease uncertainty. Similarly, results of a study using thematic content analysis to examine the life of five Swedish women who had had rectal cancer and a colostomy included participants' insecurity over cancer returning or metastasizing (Andersson, Engström, & Söderberg, 2010).

Uncertainty may also manifest as fear of embarrassment, where incidents such as ostomy leakage, odour, gas, and noise have been shown to affect quality of life (Annells, 2006; Mitchell et al., 2007; Persson & Hellström, 2002). For example, embarrassment in American Veterans with an ostomy (n = 239, 51.2% return rate) was examined using the modified City of Hope Quality of Life-Ostomy questionnaire and open-ended questions related to living with an ostomy (Mitchell et al., 2007). Among the findings, researchers noted that higher levels of embarrassment were linked to poorer quality of life socially, psychologically, physically, and spiritually; and increased reports of anxiety, depression, intimacy issues, and feelings of isolation. Uncertainty may also lead to worrying about leakage or flatulence (Andersson et al., 2010; Lynch et al.,

2008), and having enough ostomy supplies and disposal of the ostomy pouch in public (Lynch et al., 2008).

Nurses are able to help patients anticipate problems and manage their emotional distress. For example, nurses can educate patients with ideas to help them decrease the probability of encountering embarrassing situations (Mitchell et al., 2007). Nurses can also assist patients with confronting the circumstances surrounding the altered reality to help them reduce their uncertainty, such as acknowledging the permanency of their altered reality and the ensuing changes, providing education and information, and encouraging “normal” behaviours (RNAO, 2009; Selder, 1989). Mindfulness training, or the practice of being open to change in a nonjudgmental, trusting, and accepting manner, is another strategy to help patients with an ostomy transition (Trunnell, 1996). However, evaluation of this intervention is not apparent. More research on the emotional care needs of patients with an ostomy and interventions to address these needs is required.

Spiritual needs. Spiritual supportive care needs refer to “meaning and purpose in life” (Fitch, 2008b, p. 19). Transitions are influenced by meanings individuals attach to the transition experience, as well as cultural beliefs and attitudes (Meleis, 2007; Meleis et al., 2000; Selder, 1989). For example, using the Ostomy Adjustment Inventory-23 scale, it was found that Japanese participants with an ostomy ($n = 484$), were less accepting of their ostomy and the changes it entailed compared with British participants with an ostomy ($n = 464$) (Simmons, Maekawa, & Smith, 2011). Findings were attributed to possible cultural beliefs and attitudes, including the notion that Asians may perceive disabilities as morally based, self-imposed, and preventable. Hence, the study suggests

that individual cultural beliefs and attitudes may influence adjustment to an ostomy. However, it is not known how many study participants had cancer.

Attaching meaning to the need for ostomy surgery (e.g., cancer survival, symptom relief) has been found to facilitate acceptance and enjoyment of the altered reality among Swedish (Andersson et al., 2010), Brazilian (Barnabé & Dell'Acqua, 2008), and Canadian patients (Sahay et al., 2000). The spiritual quality of life of American male veterans with an ostomy (n = 239, 51.2% return rate) was examined using the City of Hope Quality of Life-Ostomy survey (Baldwin et al., 2008). Researchers found that those with higher spiritual quality of life scores (n = 59) had significantly higher scores in spiritual aspects pertaining to having a reason to live, hopefulness, inner peace, and support from spiritual or religious activities when compared to participants with lower spiritual quality of life scores (n = 61). A qualitative study of American patients with an ostomy due to colorectal cancer (N = 33) noted that spirituality was discussed the least, with only one participant stating the importance of having a faith community (Grant et al., 2011). In a Canadian study related to the transition experience of patients with an ostomy, researchers reported that few of their 20 participants with colorectal cancer reported the church (an aspect within the realm of spirituality) as a means of support, but only 11 participants had an ostomy (Sahay et al., 2000).

Mishel's Uncertainty in Illness Theory (Mishel, 1988) has been suggested as a guide for ET nurses to help patients attach meaning to their illness so that they can adapt to the experience of the illness, and thus reduce uncertainty and facilitate coping. According to Mishel, the four stages of the theory help patients add meaning to their

illness by, a) manipulating precursors that promote/reduce uncertainty, b) appraising uncertainty as dangerous/opportunity, c) using coping strategies to reduce uncertainty and to view it as an opportunity, and d) adapting to the situation (Mishel, 1988; Mishel & Braden, 1988). According to Righter (1995), the theory suggests that ET nurses should use their expertise to educate patients on how ostomy surgery may treat their cancer, and to provide support to reduce uncertainty regarding the surgery and cancer. In summary, spiritual care needs are important, but little is known about the effectiveness of the theory in patients with an ostomy, highlighting the need for more exploration into interventions that effectively address the spiritual care needs of patients with an ostomy.

Social needs. Social supportive care needs refer to patients' "family relationships, community acceptance and involvement in relationships" (Fitch, 2008b, p. 19). The influence of social stereotypes and stigmas however, may thwart a patients' healthy transition (Meleis, 2007; Meleis et al., 2000). For example, patients with an ostomy have been ostracized by their social network due to fecal odour and soiling (Doughty, 2008). Thus, socially undesirable incidents such as flatus and pouch leakage can leave patients feeling embarrassed, resentful, cautious, or fearful of social interactions (Andersson et al., 2010; Annells, 2006; Mitchell et al., 2007; Persson & Hellström, 2002).

A matched cross-sectional study of long-term (≥ 5 years), American rectal cancer survivors ($n = 246$, 54% return rate) using the modified City of Hope Quality of Life Ostomy-specific questionnaire and the 36-Item Short Form Health Survey version 2.0, found that the social wellbeing of rectal cancer survivors with an ostomy was significantly worse than matched controls (rectal cancer survivors who did not require

an ostomy) (n = 245) (Krouse et al., 2009). Patients have reported taking measures to keep their ostomy private, including changing their dress to conceal its existence (Beaver et al., 2010; Grant et al., 2011). Leisure activities such as group travelling may also be challenging because of the need to share a room and be on a bus with strangers (Andersson et al., 2010; Grant et al., 2011; Honkala & Berterö, 2009; Krouse et al., 2009; Sahay et al., 2000).

Interpersonal relationships and social support networks have been shown to address the social care needs of American (Altschuler et al., 2009; Nichols & Riemer, 2008), Chilean (Piwonka & Merino, 1999), and British patients with an ostomy (Simmons et al., 2007). These findings emphasize the importance of attending to social care needs; however, more research on Canadian-specific assessments and interventions are needed due to potential differences in cultural norms and practices.

Practical needs. Practical supportive care needs refer to “direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person (e.g., [meal planning and preparation], homemaking services, financial assistance)” (Fitch, 2008b, 19). Having low socioeconomic status may inhibit a healthy transition (Meleis, 2007; Meleis et al., 2000).

The ostomy has been found to challenge the daily routines and activities of patients (Grant et al., 2011; Honkala & Berterö, 2009; Lynch et al., 2008; Mitchell et al., 2007; Sahay et al., 2000). For example, the ostomy may make it difficult to eat foods that promote a healthy diet (e.g., fruits, vegetables, and usual high fibre foods) because of their incompatibility with the altered digestive system (Floruta, 2001). Consequently, patients have reported changing their diets (Sahay et al., 2000) to manage ostomy

output (Grant et al., 2011) and to manage fluid balance (Honkala & Berterö, 2009). In a Canadian study related to the transition experience of patients with an ostomy, in addition to emotional support, family and friends were found to be the primary source of instrumental support (e.g., assisting with chores and transportation) (Sahay et al., 2000).

Addressing socioeconomic status is particularly important for patients with an ostomy given the ongoing need for ostomy supplies (Krouse et al., 2009). Challenges in accessing, purchasing, and/or maintaining an inventory of supplies, and how these difficulties influence life after ostomy surgery have been reported by Australian (Lynch et al., 2008), American (Grant et al., 2011; Haugen et al., 2006), and Canadian patients (Sahay et al., 2000). Ontario's Ministry of Health and Long-Term Care's Assistive Devices Program provides a grant for ostomy supplies to patients with permanent ostomy status (\$600 per year per ostomy), while those receiving social assistance under Ontario Works or the Ontario Disability Support Program may be eligible to receive \$800 per ostomy (Ministry of Health and Long-Term Care, 2012b). However, there is no government funding for those with temporary ostomy status and funding differs across Canadian provinces. In a Canadian study related to the transition experience of patients with an ostomy, participants with colorectal cancer sought government financial assistance; however, researchers offered no explanation of why this was so, or what type of assistance they sought since almost half of their participants did not have an ostomy (Sahay et al., 2000).

The RNAO's (2009) clinical guidelines on ostomy care and management recommend that care plans be individualized to meet the care needs of patients and

their families, including consideration of cost and access to supplies when determining the most suitable ostomy appliance system. These clinical guidelines provide a list of ostomy supply types; contact information for manufacturers of ostomy supplies, and clothing and accessories; and financial resources. The Canadian Ostomy Assessment Guide helps non-specialized nurses choose an appropriate ostomy appliance system for their patients and has been shown to be a beneficial tool (St-Cyr, 2002). However, an ostomy supply company holds the copyright for its distribution, raising the question of its cost-benefit value after training and distribution are taken into account. This is particularly important in the home care sector where funding is already limited (Armstrong-Stassen & Cameron, 2005; Forbes & Edge, 2009; Stajduhar et al., 2011). More research is needed on how to address the financial implications that patients face following ostomy surgery across Canada given differences in funding and local resources across provinces.

Informational needs. Informational supportive care needs refer to the availability of “information to reduce confusion, anxiety and fear; to inform the person’s or family’s decision-making; and to assist in skill acquisition” (Fitch, 2008b, p. 18). Nurses are instrumental in assisting patients during a transition (Meleis, 2007; Meleis et al., 2000; Murphy, 1990), including addressing their informational supportive care needs. Nurses may address questions and concerns on stoma care (Richbourg et al., 2007) and cancer treatments (Sahay et al., 2000); offer support and teach coping strategies (RNAO, 2009); or provide assessment, follow-up, and patient education (e.g., ostomy appliance management) (RNAO, 2009). For example, a demographic information form, Survey of Perioperative Factors of Ostomy Adjustment (designed by the researchers),

and the Ostomy Adjustment Scale were used to investigate the perioperative factors that affect the long-term adjustment of American participants with an incontinent ostomy due to various etiologies ($n = 147$, 74% return rate) (Haugen et al., 2006). The study found that education received from an ET nurse was a significant factor in participants' positive adjustment to an ostomy. Results highlight the positive influence that an ET nurse's specialized knowledge may have on patients' transition to life with an ostomy.

However, patients do not always seek healthcare professionals for information, and if they do, the healthcare professional sought often depends on patients' specific informational care needs. For example, 20% of 43 American participants surveyed using a questionnaire developed by researchers (31% return rate), did not seek help when faced with difficulties, and of those who did, their choice of healthcare professional was dependent on their concern (Richbourg et al., 2007). Results indicated that nurses were participants' first choice for difficulties related to stoma care, whereas physicians were their choice for concerns related to mental health, sleep, and sexual difficulties. Information and advice received from the ET nurse was rated as being satisfactory, compared to less satisfactory ratings of non-specialized healthcare professionals such as the home care nurse, surgeon, and primary care physician, highlighting the powerful positive influence of specialized healthcare professionals. The study also noted that few participants sought support groups for coping, opting instead for a healthcare professional.

According to a 2008 report, few ET nurses exist in Canada with an estimated 250 to 300 across the country (The Canadian Association for Enterostomal Therapy, n.d.; RNAO, 2009). It is unclear how they are distributed across hospital and home care

sectors. One North American study reported that 32% of their participants (n = 743) never saw an ET nurse (Erwin-Toth et al., 2012). Consequently, many patients must rely on non-specialized nurses and other healthcare professionals for their informational care needs, potentially compromising their adjustment to an ostomy given the evidence on the positive effects ET nurses have with helping patients with an ostomy in transition (e.g., Haugen et al., 2006; Marquis et al., 2003; Richbourg et al., 2007).

Effective educational strategies to address informational care needs and to facilitate adjustment to an ostomy include programs using multimedia education, expert patients, telephone follow-ups, and telenursing. A multimedia education program improved Taiwanese patients' overall knowledge, attitude, and behaviour in self-care when compared to written information during the early postoperative period (Lo et al., 2011). An Expert Patient Program significantly improved Chinese patients' knowledge, confidence in ostomy self-care, ostomy self-management, and psychosocial adjustment (Cheng, Xu, Dai, & Yang, 2012). Telephone follow-up was a useful method to manage stoma-related problems for Chinese patients after hospital discharge (Zhang et al., 2012). A combination of traditional face-to-face home care nursing with telenursing visits was shown to be both feasible for providing support to American patients with a new ostomy due to cancer following hospital discharge, and enhanced traditional home care, improving overall satisfaction with care (Bohnenkamp et al., 2004).

A systematic review however, found that the research on nursing interventions and clinical assessment tools designed to effectively improve the health-related quality of life of patients with fecal ostomies is limited (Pittman et al., 2009). For example, the RNAO's (2009) clinical guidelines on ostomy care and management recommend using

a tool to determine the influence of ostomy surgery on patients' quality of life, and to evaluate their adjustment to the ostomy. However, an appropriate tool to do so is not specified, suggesting that the RNAO's systematic review did not find one. In addition, clinical guidelines on ostomy care and management (e.g., RNAO, 2009; Ostomy Guidelines Task Force, 2010) state that the evidence supporting ostomy care and management is often based on expert opinion and grey literature. A literature search also found few studies involving Canadian patients. Thus, it is challenging for nurses to care for and manage the care needs of patients optimally given differences in healthcare system resources across countries, and differences in cultural norms. Moreover, the quality of life and concerns of patients with an ostomy may change over time (Brown & Randle, 2005; Carlsson et al., 2010; Ito et al., 2012; Marquis et al., 2003; Pittman et al., 2009; Piwonka & Merino, 1999; RNAO, 2009), increasing the burden for nurses to identify care needs and suitable interventions during a transition.

Summary of the Literature Review

In summary, patients with a new ostomy transitioning from hospital to home experience physical, psychological, emotional, spiritual, social, practical, and informational supportive care needs, many of which are unique to this experience. It is important to understand the supportive care needs for patients with an ostomy so that nurses can provide patients with appropriate ostomy care and management. The review found that need domains noticeably overlap, illustrating the complexities of care; however, evidence of care needs and how to address them in patients with an ostomy, specifically due to cancer, following hospital discharge was limited in all domains. In addition, much of the literature focused on physical care needs, where reports of

nonphysical care needs tended to be more acknowledgements of their *influence* on patients rather than insightful evidence-based interventions or strategies to assess and assist patients to meeting these care needs. In addition, patients continue to encounter physical complications that may affect their transition to life with an ostomy despite much of the literature focused on physical care needs.

Given the role nurses play in helping patients achieve a healthy transition, the paucity of effective nursing assessment tools and interventions is particularly alarming. In addition, due to decreased hospital stays and increased reliance on home care, more time is spent recovering at home, where immediate nursing support is more limited. ET nurses have been shown to play an influential role in helping patients cope and adapt to their ostomy. However, there are few ET nurses in Canada, including in the home care sector. Leaving ostomy care to non-specialized nurses and other healthcare professionals could potentially compromise patients' adjustment to an ostomy.

The time period immediately following hospital discharge is the critical period when patients are transitioning to life with an ostomy for the first time without necessarily having easy access to a nurse or other healthcare professional. Studies examining this transition have been conducted in Japan (Ito et al., 2012), the United States (Richbourg et al., 2007) and Sweden (Andersson et al., 2010; Persson & Hellström, 2002), but there is a need for similar studies to be conducted within a Canadian context given differences in healthcare systems, resources, culture, and care practices across countries (e.g., practice guidelines, ostomy supply funding). In addition, because patients with an ostomy due to cancer must also cope with a potentially life threatening disease, understanding how cancer impacts the transition is also needed.

No studies investigating the lived experience of Canadian patients with an ostomy due to cancer shortly after hospital discharge were found using the literature search protocol. The literature search also highlighted the paucity of qualitative studies (e.g., Sahay et al., 2000), including those using phenomenology (e.g., Annells, 2006; Honkala & Berterö, 2009; Persson, Severinsson, & Hellström, 2004) and thematic content analysis (e.g., Andersson et al., 2010), related to the transition experience of patients with an ostomy. This highlights the need for a study to describe the *lived experience* of patients with an ostomy due to cancer following hospital discharge. The specific objectives of this study were:

1. To describe the experience and care needs of these patients.
2. To describe facilitators to meeting the care needs of these patients.
3. To describe barriers to meeting the care needs of these patients.

Chapter 3 - Methods

This chapter begins with a description of the research design. A description of participants (sampling, inclusion criteria, recruitment, and participant characteristics) and procedures (data collection, data analysis including methods to ensure rigor, principal investigator's [PI] background and assumptions, and ethical considerations) follows.

Research Design

A phenomenological lens based on Heidegger's (1927/2010) philosophy was used to inform the design of this study. Phenomenology is a qualitative research methodology rooted in philosophy and psychology (Polit & Beck, 2008). The methodology does not attempt to provide an answer, but rather contribute a description of how an individual lived an experience on a deeper level of understanding (Bassett, 2004; Jasper, 1994). Earlier studies conducted using quantitative methods (e.g., Herlufsen et al., 2006; Simmons et al., 2011) provide an understanding of the outcomes of ostomy surgery for patients and the multiple factors that may influence quality of life. However these studies do not provide for a deeper understanding of the lived experience of patients with an ostomy.

Phenomenology "allows the 'things' to speak for themselves while at the same time contextualizing them and ... providing greater meaning of the phenomenon under review" (McConnell-Henry, Chapman, & Francis, 2009, p. 8). Hence, the goal of phenomenological research design is to examine an individual's *lived experience*, regardless of the philosophy underlying the phenomenological lens (McConnell-Henry et al., 2009). The *essence* of a phenomenon is the fundamental constant that allows a

phenomenon to exist and reflects the *meaning* of the *lived experience* (Polit & Beck, 2008). The following section describes the two major philosophical approaches within phenomenology, Heideggerian and Husserlian, and the reason for choosing the Heideggerian approach in this study.

Husserl's phenomenological philosophy. Edmond Husserl, considered the father of phenomenology, believed knowledge came from the conscious awareness of things and that the essence of an experience was pure (McConnell-Henry et al., 2009). Hence, context was insignificant. He contended that the understanding of human experience could be achieved by studying the natural state of things in a thorough and unbiased fashion using the phenomenological reduction (Dowling, 2007), or the critical examination of something prior to exposing it to influencing prejudices. Hence, he believed that *bracketing*, or the suspension of the investigator's prejudices (*epoche*) facilitated the emergence of the phenomenon's essence (Dowling, 2007; Finlay, 1999; Koch, 1995; Thomas & Pollio, 2002). Consequently, in this type of phenomenology, knowledge is the understanding of the lived experience stripped of context; it is purely descriptive (McConnell-Henry et al., 2009).

Heidegger's phenomenological philosophy. One notable critic of Husserl's phenomenology was his student Martin Heidegger. Unlike a Husserlian phenomenological lens, which is descriptive, a Heideggerian phenomenological lens is hermeneutic or interpretive (Polit & Beck, 2008). Heidegger believed that to understand a phenomenon, one had to understand what is meant by, *to be in the world (Dasein)* (Bassett, 2004; Heidegger, 1927/2010). Heidegger believed that an individual's experiences and the meaning of those experiences could not be separated (Bassett,

2004; Johnson, 2000); hence, bracketing could not be accomplished. Context was important to Heidegger because he believed *temporality* and *spatiality* were central to being in the world since nothing could be gained statically. Time, according to Heidegger, was fluid, where past experiences influenced present and future experiences (McConnell-Henry et al., 2009); therefore, understanding the meaning of any experience required context (Johnson, 2000). A Heideggerian phenomenological lens was chosen to guide this study because it acknowledges the importance and influence of context and time, as well as space, in understanding the meaning of the *lived experience* of patients with an ostomy due to cancer as they transition to their life at home following hospital discharge.

The decision to use a phenomenological lens in this study was based on its suitability with the concept of transition. Transition theories postulate that a critical event triggers a transition, which elicits a movement from one's present reality to one's altered reality (Meleis, 2007; Selder, 1989), thereby implying that a transition occurs over a period of time due to a past event. Furthermore, during the transition, the individual is coping and adapting to the altered reality, a dynamic process which changes over time and is influenced by several factors, including one's resources (e.g., nurses) and present state of health (Fitch, 2008a; Fitch, 2008b). Hence, the concept of transition and the experience of it require both time and context for it to exist. By applying a phenomenological lens, insights into patients' lived experience, the identification of care needs, and how to support patients effectively after hospital discharge can be achieved.

Participants

Sampling. Purposive sampling was employed to recruit participants for this study to ensure the inclusion of male and female perspectives from different ages, and in various stages of the transition experience (Polit & Beck, 2008). Saturation, or the replication and/or redundancy of data, established the final number of participants (Bowen, 2008). Based on similar studies that utilized a phenomenological research design (e.g., Annells, 2006; Honkala & Berterö, 2009; Persson et al., 2004) saturation was expected after eight to ten participants (Polit & Beck, 2008).

Inclusion criteria. Eligible patients for this study included individuals who:

- (a) had surgery for a permanent, incontinent fecal ostomy due to cancer within the last year,
- (b) had been discharged from the hospital within the last year,
- (c) were able to speak and understand English, and
- (d) were 18 years of age or older and able to give consent.

However, the status of an ostomy was sometimes unknown following surgery with some patients having to wait longer than a year before knowing the ostomy status, and some patients expressing continued difficulty with adjusting to the ostomy despite having had it beyond one year. Although several patients with an ostomy were interested in participating, they were ineligible because it was unknown if their ostomy was permanent and/or because they had been discharged from the hospital beyond one year. Consequently, initial inclusion criteria (a) and (b) were modified as follows:

- (a) had surgery for an incontinent fecal ostomy due to cancer of permanent, temporary, or unknown status, and

(b) had been discharged from the hospital within the last three years.

Initial inclusion criteria (c) and (d) remained unchanged. English speaking status was necessary because the PI is a unilingual Anglophone, and the use of translators would have compromised data collection and analysis by influencing the understanding of participants' experience as described through their own words using unstructured interviews and thematic analysis (Colaizzi, 1978; Twinn, 1997).

Recruitment. Using a telephone script (see Appendix B for Telephone Script for Screening of Potential Participants by Study Site Employee), a non-clinical coordinator working from the Community Care Access Centre (the coordinating agency for home care services within Ontario) called *potential* participants to screen them for study eligibility, notified them of the study, and asked for their *permission* for the PI to contact them and to invite them to participate in this study.

Guided by the initial inclusion criteria, the non-clinical coordinator from the Community Care Access Centre contacted *potential* participants for study eligibility from a list of 66, and four individuals agreed to speak to the PI. Following the modifications to the inclusion criteria, the number of potential participants who agreed to speak to the PI increased to a total of 12. At least one of the 66 potential participants refused to participate because the experience was not pleasant.

The PI contacted all 12 *potential* participants and all of them agreed to participate (see Appendix C for Telephone Script for First Contact with Principal Investigator). A mutually convenient time was not available between the PI and the twelfth potential participant despite three attempts to schedule an interview. Of the 11 participants interviewed, the data from two participants was excluded and destroyed. Two

participants were deemed ineligible when during their interviews it became apparent that one individual had a urostomy rather than an incontinent fecal ostomy, and one individual underwent ostomy surgery due to diverticulitis rather than undiagnosed cancer. Thus, data obtained from these two interviews was excluded.

Participant characteristics. All participants were currently living with an ostomy due to cancer. Table 3.1 provides a summary of participant characteristics. All participants in the study were assigned pseudonyms. Four male participants and five female participants were interviewed with ages ranging between 51 and 90 years (mean = 66 years, median = 64 years). Diagnoses were received prior to surgery or shortly afterwards and included planned (n = 4) and unplanned (n = 4) surgeries. Unplanned surgeries were urgent or emergency surgeries (e.g., bowel obstruction, perforated bowel) which resulted in an ostomy. One participant stated that surgery was needed but it was unclear if the participant's surgery was planned or unplanned. Four participants stated that they were fully informed that their surgery would result in an ostomy and/or what having an ostomy entailed preoperatively, while four participants stated that they were minimally informed of this possibility. One participant had undergone emergency surgery but it was unclear if the participant was informed of the possibility of having an ostomy. Ostomy types included both permanent (n = 5) and temporary status (n = 4). However, all male participants had a permanent ostomy, and in one case, the ostomy changed from temporary to permanent status after two failed attempts to reverse it. Similarly, all female participants had a temporary ostomy; however, one explained that although she believed the status of her ostomy was temporary, her physician considered it permanent until it was reversed, which allowed her to qualify for

government assistance. One participant had an ileostomy, seven participants had a colostomy, and one participant had a colostomy and a urostomy. Time elapsed between hospital discharge and interview ranged from ≤ 1 month to 32 months (median = 10 months). The living state of participants included: married and living with no children (n = 4), married and living with children (n = 2), living with a partner (n = 1), and single living (n = 2). There was a wide range of work status, including retired (n = 2), retired and self-employed (n = 1), retired and volunteering (n = 1), self-employed (n = 1), employed (n = 2), employed and on disability (n = 1), and unemployed (n = 1). Seven interviews were completed in participants' homes which were located in both rural (n = 6) and urban (n = 3) settings. One interview took place at a work office (as per the participant's request), and one over the telephone (as per the participant's request).

Procedures

Data collection. To decrease the distance between the investigator and the participant, the investigator must listen to the participant openly; listening to the emerging meaning of the phenomenon rather than examining the phenomenon objectively (Johnson, 2000). To do this, data must be gathered using dialogue (Bassett, 2004), such as in unstructured interviews that facilitate a conversation (Liamputtong & Ezzy, 2005; Polit & Beck, 2008). An unstructured interview is a process of questioning participants without a fixed strategy concerning the body or course of data collected, thereby allowing the participants to share their story freely (Polit & Beck, 2008). The purpose of the interview is to examine the phenomenon within a context, acknowledging that this context will never be entirely explicit, but can hopefully be understood to provide insight into the phenomenon (Johnson, 2000).

Table 3.1

Summary of Participant Characteristics

Pseudonym	Age Range (years)	Gender	Living State	Area of Living	Work Status	Ostomy Type	Surgery Type	Cancer Stage	Cancer Treatment	Time between Hospital Discharge and Interview
Emma	51-60	Female	Married Children	Rural	E	PC	Unplanned	IV ^a	chemo postop	6 months
Mandi	51-60	Female	Married Children	Rural	E	TC	Unplanned	III	chemo postop	12 months
Andrew	61-70	Male	Married	Rural	E, D	PC	Planned	ADV ^b	chemo preop	≤ 1 month
Daphne	61-70	Female	Married	Rural	U	TC	Unplanned	III	chemo postop	7 months
Olivia	61-70	Female	Partner	Urban	R, SE	TC	Planned	III	chemo postop	10 months
Samuel	61-70	Male	Married	Rural	SE	PC, PU	Planned	III	chemo/rad preop	22 months
Alexis	71-80	Female	Single	Urban	R	TC	Unplanned	III	chemo/rad postop	10 months
Daniel	71-80	Male	Single	Rural	R, V	TI → PI	Unclear	III/IV ^c	chemo/rad postop	32 months
Craig	81-90	Male	Married	Urban	R	PC	Planned	II	N/A	1 month

Note. PC = permanent colostomy; TC = temporary colostomy; PI = permanent ileostomy; TI = temporary ileostomy; PU = permanent urostomy; R = retired; SE = self-employed; E = employed; U = unemployed; D = disability; V = volunteer; ADV = advanced; chemo = chemotherapy; rad = radiation; preop = preoperatively; postop = postoperatively

^aThe participant was unsure of her cancer stage, but stated she believed it to be a four.

^bThe participant was unsure of his cancer stage, but stated it was “advanced”.

^cThe participant was unsure of his cancer stage, but stated it was either a three or four.

Prior to data collection, the PI conducted two practice interviews with volunteers who were familiar with the study subject. One volunteer was a nurse who had experience caring for patients with an ostomy and patients with cancer. The second volunteer had had an ostomy for inflammatory bowel disease. Interviews were conducted to help the PI practice interviewing, transcribing, and coding, and to confirm interview questions addressed study objectives, but were adequately broad to capture the experience. Volunteers consented to the interview and provided the PI with feedback regarding the interview questions' appropriateness for the objectives of this study, as well as her interviewing technique. The PI and thesis supervisor reviewed the volunteers' feedback and transcripts, which indicated that no changes were required to the interview protocol. Practice interviews were not included in the data analysis.

Ten interviews were conducted face-to-face, and one over the telephone (as per the participant's request). Participants provided consent prior to commencing the interview (See Appendix D1 and D2 for Participant Information Letter in English and French respectively; and Appendix E1 and E2 for Consent Form for Participant in English and French respectively). The PI used in-depth, unstructured interviews to collect data. The PI also kept interview notes to help capture the nonverbal essence of the interview (e.g., facial expressions). The PI first asked participants to explain how they came to require ostomy surgery to give background or context to their answers. Then, the PI asked three broad questions to elicit perspectives on their transition to life with an ostomy (see Appendix F for Interview Schedule):

1. Can you tell me what it has been like for you living with an ostomy since you were discharged from hospital?

2. Has there been anything particularly difficult for you?
3. What has helped or hasn't helped?

The unstructured interviews took the form of informal, one-on-one conversations, most of the time over tea or snacks sitting at the kitchen table or on the couch in the family room. In one case, a participant's wife joined the conversation part-way through as their home's open concept facilitated her participation (consent was obtained). At times during the interview, participants smiled, chuckled, and laughed, while at other moments of the conversation they became tearful, needing time to pause and take a breath before continuing with their story. Interviews ranged between 35 and 158 minutes (mean = 1 hour and 32 minutes, median = 1 hour and 20 minutes), allowing participants to readily share private details and provide detailed descriptions of their experience.

The PI audio recorded interviews and began transcribing them verbatim within one week of their completion. To enhance readability, utterances such as "um", "uh", "er", "Mmmm", "Hmmm", "you know", "right", "Oh, okay" and "Okay" were deleted. Stuttering (e.g., "S- S- She") and repeated words (e.g., "the the") were also deleted.

Data analysis. Gathering data is limited by the questions asked. Therefore, the phenomenon will always remain partially undiscovered (Johnson, 2000). Consequently, qualitative data analysis must be fluid; the PI moved between questioning and examining the text to develop a pool of ideas to determine the meaning of participants' lived experience (McConnell-Henry et al., 2009). The phenomenon is examined as a whole and by its parts, taking an ontological view where multiple possibilities of being are revealed (McConnell-Henry et al., 2009).

Hence, hermeneutic phenomenology recognizes that experiences have context and are unique to individuals, allowing for multiple realities (Koch, 1995). Transcripts were analyzed inductively using a thematic analysis according to Colaizzi's (1978) data analysis method as described:

1. "Read all of the subject's descriptions, conventionally termed *protocols*, in order to acquire a feeling for them, a making sense out of them" (Colaizzi, 1978, p. 59). The PI read all transcripts thoroughly prior to creating categories or themes to immerse herself in the data to achieve this step.
2. "Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon; this is known as *extracting [a] significant statement*." (Colaizzi, 1978, p. 59). To do this, the PI reviewed each transcript and interview notes to identify significant text (coded text).
3. "Try to spell out the meaning of each significant statement, known as *formulating meanings* ... [making sure to] not formulate meanings which have no connection with the data" (Colaizzi, 1978, p. 59). The PI created a category for each coded text to complete this step.
4. "Repeat the above for each protocol [i.e., steps 1 through 3], and organize the aggregate formulated meanings into *clusters of themes* ... [referring] these clusters of themes back to the original protocols ... to *validate* them ... [refusing] temptations of ignoring data or themes which don't fit, or of prematurely generating a theory which would merely conceptually abstractly eliminate the discordance of ... findings thus far" (Colaizzi, 1978, p. 59, 61). To achieve this, the PI organized categories into clusters

of over-arching themes, with constant referral to the original transcripts to verify the over-arching themes. Discrepancies within and/or between the developing over-arching themes were noted, and caution was taken to avoid ignoring data or categories that did not fit within the over-arching themes by repeating steps 2 through 4 as necessary. Hence, the PI attempted to “stay close to the data” by re-reading and referring to transcripts to ensure over-arching themes emerged from the words of the participants.

5. “The results ... are integrated into an *exhaustive description* of the investigated topic” (Colaizzi, 1978, p. 61). To do this, the PI synthesized results into an in-depth description of the phenomenon.
6. “An effort is made to *formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible*” (Colaizzi, 1978, p. 61). To accomplish this, the PI formulated the in-depth description into a definition of the phenomenon’s essence.
7. “A final validating step can be achieved by returning to each subject, and ... asking the subject about the findings ... *Any relevant new data that emerges from these interviews must be worked into the final product of the research*” (Colaizzi, 1978, p. 61-62). The PI completed this step through *member checks*, or follow-up interviews with participants, where they were asked to verify a summary of the preliminary findings to ensure credibility of the data (Guba & Lincoln, 1989; Polit & Beck, 2008). Two participants were specifically chosen for member checks to represent the

diversity within the sample. Member checks revealed that preliminary findings reflected participants' experiences with only minor changes.

Decisions made throughout data collection and analyses were noted to reflect the PI's own perceptions, and to create an audit trail (Polit & Beck, 2008).

Methods to ensure rigor. Guba and Lincoln's (1989) framework was used to establish trustworthiness or confidence in the findings (i.e., credibility, dependability, confirmability, and transferability). *Credibility* or confidence in the truth of the findings and interpretations of them was achieved by, a) making assumptions explicit prior to data collection, b) engaging with participants to understand their lived transition experience using in-depth, unstructured interviews, c) having the thesis supervisor and a fellow graduate student not involved in the study, both of whom are familiar with the study subject, double-code selected transcripts to verify the developing coding scheme, (*Double-coding* is a process in which two individuals independently extract significant statements from the same transcript based on a protocol, and then compare their analyses to validate the protocol.) d) having the thesis supervisor and committee members who have expertise in qualitative research and oncology, and familiarity with the study subject, review selected transcripts to verify the PI's thematic analysis, and e) conducting member checks using follow-up interviews with two participants who represented the characteristic variety of participants to ensure that the preliminary findings reflected their experiences (see Appendix G for Summary of Preliminary Results for Participant Review). *Dependability* or the "stability of the data over time" (Guba & Lincoln, 1989, p. 242) was achieved by tracking decisions and rationales to create an audit trail for future reference. *Confirmability* or certainty that the data, analysis of the data, and results of the study

derived from the information provided by the participants, was achieved by independently reading and re-reading transcripts and interview notes to identify significant text/phrases to create categories/themes (coding process). The process involved continuously consulting with the thesis supervisor to review and analyze selected transcripts and coding schemes that the PI produced. To ensure reliability, a graduate student researcher, independently coded a selected transcript. Any disparity in findings were noted and debated until a consensus was reached, taking caution to avoid ignoring data that did not fit over-arching themes, thereby allowing for and verifying that themes emerged from the data (Colaizzi, 1978). Once preliminary findings of thematic analyses were completed, committee members were consulted to review the findings of thematic analyses, based upon two representative transcripts. Any differences in findings were noted and discussed amongst the PI, thesis supervisor, and committee members until a consensus was reached, again taking caution to avoid ignoring data that did not fit over-arching themes. The PI attempted to “stay close to the data” by re-reading and referring to the transcripts to ensure themes emerged from participants’ words. In addition, personal interpretations of the data were tracked to ensure the PI’s personal feelings and experiences did not replace those of the participants. *Transferability* and/or applicability of the data to other groups was achieved through detailed description of the context, time, and place in which this study occurred; allowing readers to determine the applicability of study results to other persons and contexts.

Principal Investigator’s background and assumptions. Interpretation follows all experiences and is based on an individual’s background (*historicity*) (Koch, 1995). Individuals are born into the world with a background that is shaped

by a culture which existed before their birth, and it is this culture which facilitates understanding (Bassett, 2004; Koch, 1995). Hence, individuals have a *pre-understanding* or *fore-structure* of the world that is already present at birth and so, cannot be bracketed (Bassett, 2004; Koch, 1995; McConnell-Henry et al., 2009). In other words, an individual's experiences and the meaning of those experiences cannot be separated (Bassett, 2004; Johnson, 2000). To be understood, individuals must bring their background into the foreground (*fore-conception*) (Bassett, 2004; Koch, 1995). It is individuals' backgrounds that allow them to be in the world or *Dasein*; to find meaning in the world (Bassett, 2004; Koch, 1995).

My assumptions were made explicit prior to data collection to increase credibility, or confidence in the truth of the data and interpretations. My being was shaped by my experiences as a general surgery and gastroenterology nurse in an Ontario acute care hospital, caring for patients with an ostomy, as well as for patients with cancer. The being of participants in this study was shaped by their experience of having undergone ostomy surgery and been diagnosed with cancer, and how they identified themselves as a person. Consequently, because my background cannot be bracketed, the understanding of participants' experiences can never be neutral because I inevitably co-participate in making the data (*co-constitution*) (Johnson, 2000; Koch, 1995). My attempt to understand the lived experience of patients with an ostomy due to cancer following hospital discharge was approached with the beliefs that a) the health care system and healthcare professionals influence patients' transition experience through the care that they provide to them, including direct clinical practice and education; b) patients are multidimensional, and their care needs are assessed best using a holistic approach

to care; c) following ostomy surgery, patients must learn to live a different way of life; and d) patients who need help will ask for and accept help when offered by others.

Ethical considerations. Prior to starting this study, ethical approval was received from the University of Ottawa Health Sciences Research Grants and Ethics Board (see Ethical Approval Notice I – Access to Participants for Data Collection; Ethical Approval Notice II – Approval of Modified Inclusion Criteria; and Ethical Approval Notice III – Renewal for Member Checks in Appendix H1, H2, and H3 respectively). A local Community Care Access Centre executive administrator with Client Services provided consent to access participants (see Appendix I for Letter of Support for Site Access and Appendix J for the Signed Consent for Site Access).

To ensure confidentiality and anonymity, code numbers were used instead of personal identifiers on all study documents, including transcribed interviews. Audio and digital data were further safeguarded using password protection. The master list and audio data were kept separate from all other data in locked cabinets and accessible only by the PI. Results were reported as grouped (aggregate) data so that it was not possible to identify the study site or individual participants. In addition, direct quotes had identifying information removed, including information about other participants and non-participants, and the study site; and code numbers were replaced with pseudonyms.

To ensure security, the master list, and paper, audio, and digital data will be stored for five years following study completion in separate locked cabinets at the University of Ottawa, Nursing Best Practice Research Centre, after which time the master list and study data will be destroyed. Shredding will be used to dispose of all paper materials. Secure deletion will be used to dispose of all digital and audio data.

Chapter 4 – Findings

The following chapter will present the results of the study. The chapter will begin with a description of the essence of participants' lived experience. A description of themes and sub-themes will then be presented with their definition and participant quotes.

Adjusting to a New Way of Living

The lived experience of patients with an ostomy due to cancer following hospital discharge is illustrated in Figure 4.1. This experience is reflected by four major themes and 11 sub-themes. The essence of the experience is expressed as

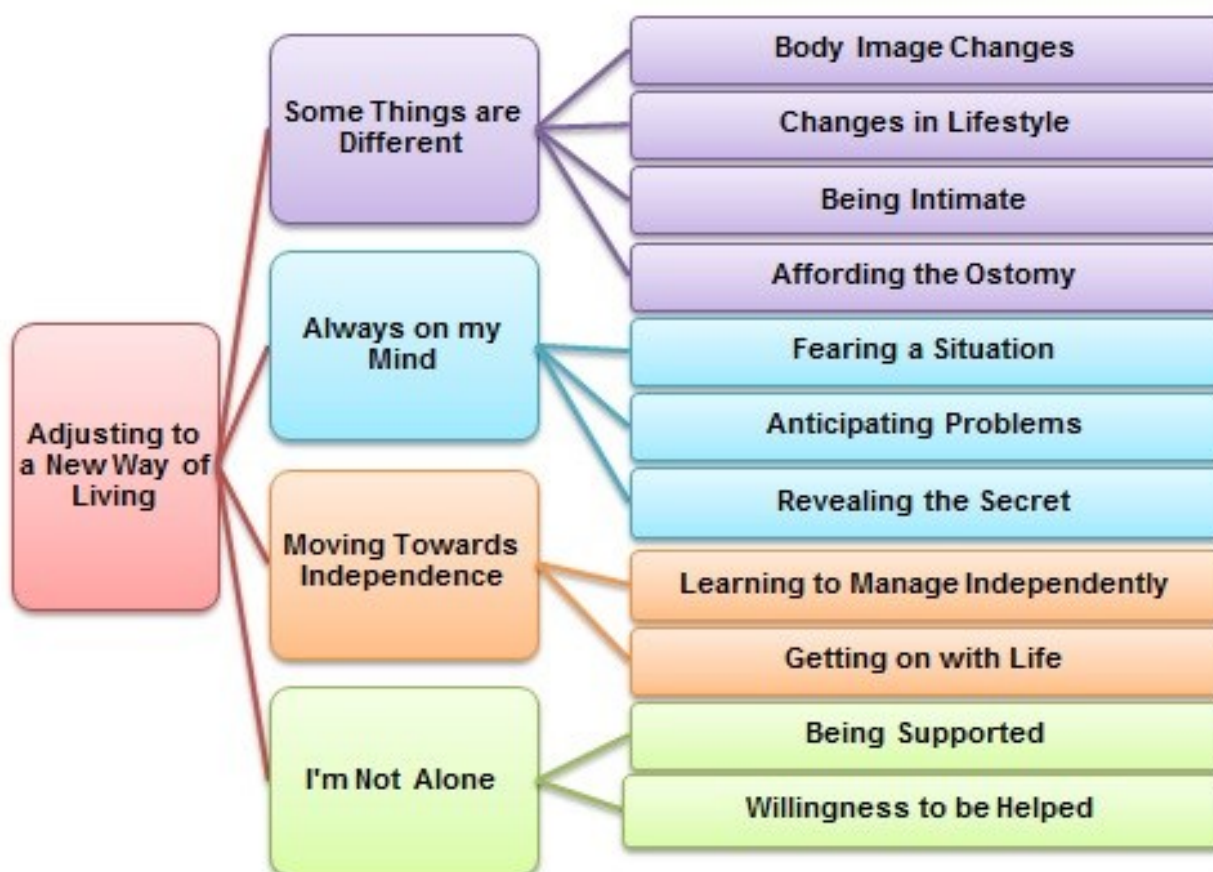


Figure 4.1. The Lived Experience of Patients Following Hospital Discharge.

Adjusting to a New Way of Living. It is defined as the patient's experience of being supported throughout the process of learning to adapt to the physical, psychological, emotional, social, and financial changes that accompany ostomy surgery due to cancer, as she or he strives to live independently.

The essence, *Adjusting to a New Way of Living*, highlights the participants' transition experience from life before an ostomy to life with an ostomy due to cancer. The specific details of the experience varied amongst participants because each individual lived within a different context. However, when the experiences were examined as a whole using a phenomenological lens, shared themes emerged that included; *Some Things are Different*, *Always on my Mind*, *Moving Towards Independence*, and *I'm not Alone*. There was a common quintessence interwoven amongst the themes that involved coping with a change that could not be undone. Having to undergo ostomy surgery because of cancer changed participants and the life they lived, and the significant characteristic that was shared amongst all participants was that, despite all of the changes they endured, they learned and strived to live their changed life independently. Participants were transitioning to a new reality, one that included an ostomy and a cancer diagnosis.

Some Things are Different

The first major theme *Some Things are Different* refers to participants' awareness that changes have occurred following ostomy surgery due to cancer. Ostomy surgery due to cancer changed how all participants perceived themselves whether from a physical or an emotional perspective. This was evident whether participants compared themselves to their past self or to others with regards to the ostomy or cancer. The theme was illustrated by Daniel who stated:

I figured ... when he's finished fooling around in [there], doing all that in there, then he just sews me back up. And then I'm on a liquid diet and all that.

That's what I expected; totally! But then when I woke up and everything was totally different! I had the stitches and all that and everything, but I also had these two pieces sticking out here [referring to ostomy site]!

From the moment participants awoke from their surgery, their body image and overall lifestyle changed, which were difficult to ignore. Daphne shared, *"I find that [change in my activities is] challenging. ... I don't sick well. ... Some people do it well; I don't. I would rather just kinda ignore it. But you can't!"* All participants described the theme *Some Things are Different* which includes the four sub-themes *Body Image Changes*, *Changes in Lifestyle*, *Being Intimate*, and *Affording the Ostomy*.

Body Image Changes. The sub-theme *Body Image Changes* is defined as the emotional response to the physical changes resulting from the ostomy surgery. All participants described examples of *Body Image Changes*. As Alexis explained, the physical change forced her *"to adjust to a new state of going like that [referring to having a bowel movement]!"* stating, *"[It is] not regular to go [chuckling] ... other than the place one knows"*. Unlike the cancer diagnosis, the ostomy provided visual evidence of physical change. Olivia stated, *"The ostomy was more of a horrible shock to me than a cancer diagnosis. ... A cancer diagnosis; well, it is what it is. But the ostomy is very visibly what it is! [Laughing] It's really horrible!"* For Craig, his regular prostate exam provided further proof of how he changed physically. He laughed, *"How can you check my prostate? ... It's still there! ... But the normal way of*

checking is no longer there!” For Daphne, making light of the situation did not ease her awareness of being different:

The nurses they always talk about, ‘Oh, well. So what? So you’re not pooping out of your bum, you’re pooping out of this.’ Well ya, but I mean it’s different! [Laughing] And they kind of try to make it light hearted and everything. I’m thinking, ‘Ugh! Not really, no.’

In addition to the physical change influencing their body image, participants also *felt* different since having the surgery. Emma explicated, *“I think you just look around, [and] you feel totally different. You feel like you’re a different person.”* For Andrew, the ostomy was *“disappointing ... [and] somewhat degrading”* and made him feel *“less of a human”*. For Mandi, the physical nature of the ostomy impeded any efforts made to feel normal:

I found it was something it was always there. Like every morning, I woke up, it was there. ... Like, there was times you could forget you had cancer. You ... felt like you could kinda be normal. But not with that because that was always [going]. ... I never ever got it [controlled] ... so it wouldn’t be going.

Feeling different about their body image was further illustrated when participants compared themselves to others. Daphne stated, *“Unless you actually have one ... [you] don’t really know,”* conveying that only people with an ostomy could truly understand her. For Samuel, being different from others was associated with the cancer rather than the ostomy. Samuel could not relate to other patients with cancer, stating, *“I found it very, very hard ... driving with them [to appointments], to listen to them [talk about their cancer]. ... [and] what they’re going through. And I found that I don’t fit in here.”*

Changes in Lifestyle. There was no escaping change in lifestyle following ostomy surgery due to cancer. The sub-theme, *Changes in Lifestyle* is defined as the alterations in participants' everyday routines and way of life following ostomy surgery due to cancer. It describes physical, social, and practical changes. As life carried on, participants became aware of the extent of the change. Similar to changes in their body image, ostomy surgery due to cancer also changed participants' daily activities and way of life. Daniel stated, *"Be prepared for a major change in your lifestyle."* All participants described *Changes in Lifestyle*; however, changes were context dependent because each individual lived a unique lifestyle and a certain complexity of illness and surgery. Hence, the change experienced differed amongst participants, and its impact was dependent on the magnitude of change incurred on participants' individual lifestyles. Changes involved various aspects of participants' lives and are described under three categories within this sub-theme. The categories detail how participants' lifestyle changed, with the second being heavily influenced by the first, and include, a) diet and bowel routine, b) social life, and c) daily activities.

Diet and bowel routine. The first category in the sub-theme *Changes in Lifestyle* refers to changes in participants' diet and bowel routine (bowel output and cleanup process), that all participants experienced. Having an ostomy required diet changes because diet affected bowel output (stool, flatus, noise) as explained by Daniel who said, *"It will inflate like a balloon. ... depending on what you ate, or drank"*. Participants learned to manage their bowel output through their diet, resulting in changes to their diet. Changes in diet included having to stop eating certain types of foods and reintroducing others. Emma shared, *"We had to go back*

to white bread. We had to go back to all cooked vegetables, nothing fresh; and all that kind of stuff.” For Samuel, the ostomy surgery allowed him to indulge in foods he was not able to eat preoperatively, *“I never could eat cheese or any of that stuff before ‘cause I used to get blocked up, eh? ... And now I can. [Laughing] ... I guess there’s some things better.”*

In addition to changes in diet, participants also experienced changes in their bowel routine which were reflected in their description of bowel output and cleanup process. Andrew voiced how he thought the ostomy output was *“really rank!”* forcing him to *“put a couple of incense candles in the bathroom”*. Being aware of bowel output was especially important due to the incontinent nature of the ostomy. Daniel described, *“When your ileum pops that stuff out of there, it’s not going back in [there]. There’s no way it’ll allow it back in,”* and proximity to a bathroom facility was described as a necessity. Change in the frequency of bowel output *“was a nuisance”*. Alexis explained:

It’s a nuisance thing; when you’re used to going once a day to the bathroom and [then] going several times. ... That’s the one thing I could do without. ... [Before the operation the] most you go [is] twice a day if you eat something disagreeable ... But [now,] to have that irregularity on a daily basis, it’s not fun. It’s not. Even though it’s not painful, it’s a nuisance thing.

For Samuel, the change in bowel routine was more of a relief, stating, *“I get up now ... in the night, and I have to go maybe twice in the night to drain myself, eh. But, it’s okay. ... [Because] you never get constipated!”* For one participant, being close to a bathroom facility was nothing new due to a history of inflammatory bowel disease.

In addition to bowel output, change in bowel routine also included participants' cleanup process. Alexis explained, "... *your paper towels and your hundred rolls of toilet paper. You use much more than you used to.*" Numerous items were often needed for the cleanup process, including an assortment of appliance pieces (e.g., flange and pouch), accessories (e.g., belts), pastes, tapes, skin protectors, and cleaning solutions (including normal saline), all of which depended on the participants' ostomy appliance system. For two participants, changes to the bowel routine involved the onset of rectal discharge, which forced them to include incontinent pads to their list of personal care items.

For participants undergoing cancer treatments, an added layer of change was experienced in their lifestyle. Similar to other patients undergoing cancer treatments, participants also experienced side-effects such as stomatitis, neuropathy, increased susceptibility to infections, fatigue, and/or changes in memory, hair, and skin. Three participants who underwent cancer treatments voiced how their treatments specifically affected their diet and bowel routine. In Alexis' case, she described:

From going once a day to going like ten times a day! Oh Lord! Plenty! Plenty! Even now you go, but not with the frequency [it was during cancer treatment]; now it's half [of that]. ...I was going ten, twelve...! Plenty! ...for the period, the six month period [of cancer treatment]... You couldn't catch yourself.

Emma also experienced a change in her bowel routine, as well as diet during her cancer treatments, changes which affected her family. She explained:

They say at home too that the toilet I use, nobody else should use [it]. ... 'specially when I'm on the bottle [for chemotherapy]. And then, also I should,

if I'm eating something, I shouldn't then share it with somebody. ... And my glass that I drink out of and stuff like that. Like nobody else drinks out of that

Participants experienced change in both their diet and bowel routines, and although participants experienced different bowel routines, they all experienced a change from their previous routine. For some participants' these changes were further impacted by their cancer treatments.

Social life. The second category in the sub-theme, *Changes in Lifestyle*, describes how changes in participants' diet and bowel routine influenced their social life, which refers to interacting with others, and was described by seven participants. Daphne described the connection between diet and bowel routine – specifically output – and social life:

Going out's not ... I don't find it comfortable, 'cause you just never [know]; you never know ... we went out to ... a little vegetarian restaurant and ... [I] made the mistake of having onion soup [chuckling] ... [I] spent the rest of the day looking for a bathroom just to get rid of gas that was constantly collecting. So it's sort of a nuisance more than anything.

Similarly, Alexis stated, *"One has to regulate the food and you could do it at home. If you go out you're more at the mercy of whatever people give you."* Going out in public also meant having to deal with the incontinent nature of the ostomy in a less controlled environment. Alexis added, *"...you don't want to be making noise ... you don't want to get too carried away and get loose in the town. Because you could be ... just sitting on the bus [when something happens]."* In addition to bowel output, the cleanup process also affected one's social life. Alexis explained, *"You don't want to use other people's bathrooms [because of] ... [the] cleanup process. Listen. In my*

bathroom, I have all my equipment in there for cleaning". Items required for cleanup were extensive and thus participants became reluctant to leave their home where all their necessary items for cleanup were readily available.

Cancer treatments also affected the participants' social life. Some participants purposely reduced their public social engagements such as attending church services because of fatigue and increased susceptibility to infections. Emma shared how cancer treatments changed her social life:

... our [coworkers] ... have four kids and I used to babysit them. ... we've been really, really careful that when I'm on the bottle [for chemotherapy], nobody comes around me. ... we used to get together, two or three time a week. ... we really haven't done that. ... they're growing and changing so much every day that I don't want to ever think that I had stopped something, or something with the chemo ... So I've been overcautious maybe, but I'd rather be overcautious than not ...

For Alexis, changes in her diet and bowel routine while on cancer treatments limited her time socializing in public, stating, *"I will go out and time it and say, 'I don't want to be longer than two hours.'"* Change in participants' social life was shown to be connected to change in their diet and bowel routine, and for some, this was further affected by their cancer treatments. Hence, change in one aspect (or category) of participants' way of life did not necessarily occur in isolation; aspects were all interconnected.

Daily activities. The third category in the sub-theme *Changes in Lifestyle* involved changes in daily activities, which refer to alterations in participants' everyday routines such as shopping, dress, lifting, working; and physical and

recreational activities such as travelling, camping, and gardening. Eight participants described changes in their daily activities. For example, Emma explained how her shopping routine had changed, stating, *“I still don’t go shopping by myself.”* All four male participants experienced changes in their dress because of the location of the stoma. Craig elaborated:

To me, the greatest discomfort with this is the fact that I can’t wear a belt anymore. Ain’t that amazing? It’s little things like this, supposedly now that I have to wear suspenders ... because of the position of the stoma. ... my clothes at the waist has to be a little bigger.

For Olivia, changes in dress were not due to stoma location, but because she was feeling *“body conscious”* and *“couldn’t bear to wear a bathing suit”*.

Change experienced in one area of daily activities affected another. For example, Samuel and Emma voiced changes in what they were able to lift. Samuel explained, *“Twenty-five pounds they told me [was my limit] ... I can lift 50 pounds; 75 pounds ... I knock those things off! [Laughing]”* For him, the limitations affected his work, which involved heavy lifting, but for Emma, they affected her ability to perform housework.

Physical and recreational activities also changed. Daniel voiced several examples of change, including chain sawing and backcountry camping, stating, *“I can’t anymore. ... Since all this; ya. I’ve had to stop that totally.”* Similarly, Daphne shared, *“I can’t do a lot of [the] things that I would normally do. Like I was taking yoga ... like physical activities ... gardening. So, after I had my operation ... I wasn’t able to do anything pretty well.”* The travelling routine of three participants was also altered due to changes in their bowel routine. Daniel clarified:

Well I have my ... [work] bag there but I have that other kit ... I carry [it] all the time travelling. And it's all the change stuff that you need for the ileostomy. So it's a [kit for] spare ... pouches and the flange.

Daphne shared how cancer treatments changed her daily activities, illustrating that changes in one's lifestyle were not solely due to the ostomy, but also due to the diagnosis and treatment of cancer:

Once they have a [peripherally inserted central catheter] line [in your arm], so I'm not allowed to do any kind of repetitive [movements], or ... lift anything heavy ... Ya; I guess that's a challenge, not being able to do [the] physical things that I was able to do before.

Although the specific details of change in participants' daily activities varied extensively due to their individual lifestyles and complexity of illness and surgery, they shared a *change* in the types of daily activities they chose or the way they engaged in their activities. Moreover, change in one daily activity impacted another, and change in daily activities was not solely related to the ostomy, but to the cancer as well, including cancer treatments which added an additional layer of change.

Being Intimate. Engaging in intimacy, whether sexual or nonsexual, also affected participants' significant other. The ability to share a deep, personal connection with a significant other postoperatively defines the sub-theme *Being Intimate*. It was described by eight participants during data collection and another during interviews for member checks. Participants described the psychosocial effect of ostomy surgery due to cancer had on their intimate relationships. They described how opening oneself up while in an already vulnerable state required personal readiness and understanding, and acceptance from a significant other, particularly in

regards to sexual intimacy. They also stressed the importance of intimacy for both them and their partners, and provided examples of how the surgery and cancer negatively impacted their ability to engage in sexual intimacy. Some participants even shared that intimacy was inadequately addressed.

Engaging in sexual intimacy was a *“Total huge issue!”* for participants, as stated by Olivia. As a single participant, Alexis described how the ostomy was a deterrent to engaging in intimacy, stating:

If you're in love with people, you want to get closer ... But this is a turn off to get closer. [Chuckling] ... If you know this person is impeded in all these ways, why would you bother? ... Thank God that's not one of my problems!

Resuming sexual intimacy required readiness on the part of participants, and patience on the part of partners. Alexis explained, *“You got to really love him eh; to want to come to me ... in any state like this. I mean you got to love me for me”*. For example, when partners were understanding and accepting, participants' uneasiness with engaging in sexual intimacy decreased. Olivia said:

It was a one way street for quite a long time! [Chuckling] Until I said, 'Okay, I think I'm ready now.' ... I just had to accept that he was accepting! ... And he's been absolutely great! But he's understood my reluctance. ... It was a big issue. Very difficult. ... [The] approach each of us had was well, it'll be what it will be. And take your time. And when it's ready it's ready.

One participant described how despite having a history of erectile dysfunction, ostomy surgery still affected his sexual relationship with his spouse. Samuel stated, *“It does affect your sex life too, eh ... So that's not the same anymore.”* Samuel went on to describe how the change in his sexual relationship with his wife affected both

of them, *"... It's hard for her too, and, I feel bad about it, eh. You know I still have the feeling for her and everything ... I feel bad for her a lot of times too ... I know she's down on stuff,"* underscoring the importance of intimacy for both individuals. Despite the change in their sexual relationship however, Samuel's spouse expressed acceptance of their new intimacy issues. However, for one single participant, Daniel, the inability to perform sexually resulted in his relationship ending. He stated, *"It becomes a 'No. No.' I guess. ... I was going with a girl up here, and it just fell apart. ... Well, when you can't perform. ... It's not a happy thing!"* Mandi said she had not shared a bed with her spouse since the surgery 12 months ago, and described a negative strain on their relationship. Not all participants experienced *change* in sexual intimacy, as was the case with Andy, who had a history of erectile dysfunction, and Craig, who explained during interviews for member checks that nothing had changed between him and his wife because preoperatively they had not been sexually intimate for some time. Instead, both Andy and Craig engaged in intimacy with their wives in other ways such as companionship.

Intimacy was further challenged for two participants undergoing chemotherapy. Daphne explained, *"Being on chemo ... you worry about ... fluid exchange and stuff like that ..."* Emma elaborated, *"They told us not to sleep together when I'm on the chemo. ... most nights ... he is sleeping in another bed."* Emma continued, *"sometimes you do lie there and you get really, really lonely. And you kinda think, 'Ugh! Crap!'"* For Daphne, the idea of resuming sexual intimacy was *"very complicated"* due to the risk of fluid exchange and *"sure as hell not worth sex! [Chuckling]"*. However, intimacy was resumed in other ways. Emma stated, *"But lots*

of times he'll just come in and say, 'I just want to hold you for a while;' and stuff like that. Which again is important."

Discussions with healthcare professionals regarding intimacy varied. Samuel explained how he was not informed about the effect that surgery would have on his sex life:

No, they didn't [tell me about how the surgery would impact my sex life]. No. No; I wasn't even told that! ... 'Til she [referring to wife] was reading about it and she told me. ... She was the one who told me, eh ... They didn't tell me about it ...

Emma shared how the subject was discussed at her chemotherapy lesson, stating, *"They talked about having sex and stuff and to use a condom and all that."* Olivia explained how she would not discuss the subject with healthcare professionals, laughing, *"I wouldn't discuss that with a healthcare professional; thank you very much. No. ... I think they tried. I just don't have that kind of discussion with them."*

Affording the Ostomy. Participants had the added expense of affording ostomy supplies. The sub-theme *Affording the Ostomy* is defined as the challenges and strategies of purchasing, obtaining, and managing an inventory of ostomy supplies within one's budget. Eight participants shared their experiences and at least four of these participants expressed some form of obstacle with affording, obtaining, and/or managing an inventory of supplies.

The cost of supplies was influenced by the type of ostomy appliance system used (e.g., one piece vs two piece; belt vs no belt) and the frequency of appliance changes. Daphne shared:

I get about five or six days out of one appliance. So if I'm changing it five ... or six times a month ... like you get ten pouches in a box and you get five flanges. So you need two boxes of flanges and one box of pouches which comes out to over \$200. ... Some people have to change them more often; [that adds to the cost]. ... [and] there's all different qualities too; so.

Depending on what you can afford.

Two participants experienced rectal discharge and required incontinence pads, which added to their expenses. Daniel explained:

I have the [added] expense of [incontinence pads] ... At present, I can get away with just wearing it to bed; like overnight. ... That's a dollar every night. So that's another \$30 a month. ... And not covered by [the] government or anything ...

Participants sought financial assistance for supplies. Daphne explained, "My husband has insurance at work that covers 90% of [my supplies]". Others sought financial assistance from the government. Daniel explained, "Twice a year they [the government] gives us ... \$600 in total. I'm not too sure but probably 40% [of the ostomy supplies works out to be covered] ..." However, as Alexis explained, government funding required certain qualifications.

There are two conditions [for government funding. The first is] when it's designated permanent; and mine was temporary. So I didn't qualify really for that. And another stipulation [is] you must have, only a certain amount in the bank. You must be dire poor.

When participants did not have insurance coverage or meet the eligibility requirements for government assistance, they were left to finance their supplies on

their own. Samuel pointed out that there was the hope of extra assistance, *“I’ll be 65 in February. ... after 65 lotta your drugs and the cancer looks after you ... So I’m glad to get old. [Laughing]”* (Ontarians aged 65 years or older are eligible for the Ontario Drug Benefit, which covers certain prescription drug products, but not ostomy supplies [Ministry of Health and Long-term Care, 2012a].) For Samuel, extra help was needed because his second ostomy doubled his expenses.

In addition to financing the ostomy supplies, participants also needed to obtain them. All participants received home care assistance following hospital discharge and were able to receive supplies through them. However, as Emma explained, the selection of supplies was limited. Thus, qualifying for government assistance allowed her the freedom to choose supplies that best suited her needs. She stated. *“... it was difficult when we were just under [the Community Care Access Centre] ... [because they had] limitations as to what [the home care nurse] could order and stuff.”*

Affording the ostomy was particularly difficult for participants who were retired or were unable to work. Daniel stated, *“Every time you ruin one of those; I mean it’s another \$25! Like they’re not throw-aways. ... They’re monetary. I have to look at the monetary situation. I’m retired strictly on government ... pension.”* For another participant Andrew, the cancer and surgery prevented him from returning to work which left his wife to carry the financial burden until he was able to receive government disability assistance.

Participants developed strategies to help relieve their financial burden. Alexis for example, asked for help from her family, stating, *“They’ve done beautifully; everybody championed the cause sort of speak. ... my gifts ... go towards supplies*

or nutrients.” Emma explained how she requested samples to help cover supply costs:

You can actually email the company and say, ‘I’m not using your product at this time, but do you have any samples ...?’ And they will send you those free samples. So that you don’t end up buying a whole box of pouches or a whole box of flanges and then you don’t use them.

Participants also developed individual strategies to increase the longevity of their appliance, such as using tape. Alexis revealed:

I ... was trying to find a way where I [would] spend less and I’m saying these flanges are coming off [easily] ... I know what I’m going to do; buy a tape so strong that it can’t [come off easily] ... [Chuckling] I bought hockey tape and then the nurse say, ‘No, that would rip all your skin off.’ ... [But] it has helped me! I wouldn’t advise other people if they’re careless. I take a lot of care with it.

Another strategy was to wash or reuse bags. Alexis shared why associated risks did not deter her:

I learned to wash the bags, and it wasn’t a good suggestion to me. My counsel said that you could encourage infection ... But I don’t have the means to keep buying those things on non-stop. You get drained in not only physically, but financially too.

Similar to other patients with cancers, participants also had the added expense of travelling to and from medical appointments and cancer treatments, illustrating that their experiences with the ostomy could not be separated from their experiences with cancer. The frequency of appointments and expense of travelling

was especially challenging for those living in rural areas. Daniel stated, *“I’ve always driven to [the city] myself. ... It cost me well over \$100 a trip.”* Andrew added, *“One of the biggest things that hit me was all these appointments ... Like when this first started ... there was something like 23 appointments in something like 30 days. ... And some of them were useless trips”.*

The major theme *Some Things are Different* described how every aspect of participants’ lives and sense of self and body changed following their ostomy surgery and cancer diagnosis. Participants’ stories revealed how they changed physically, emotionally, and financially. They shared how their entire lifestyle was altered, with changes in one aspect of their lives influencing other aspects, whether due to the ostomy or to the cancer. Change also affected the people around them, particularly the intimate relationships that they shared with their significant other. Their lives were altered and finding psychological relief from all the changes was not always possible, as will be discussed in the second major theme, *Always on my Mind*.

Always on my Mind

The major theme *Always on my Mind* refers to the participants’ constant awareness of the uncontrollable nature of the ostomy, which compels them to continuously think about preparing for and preventing uncomfortable situations from occurring. Seven participants described the theme during data collection and another during interviews for member checks. Daniel described this theme succinctly when he stated:

You have to have it in your mind to be prepared for the situations. ... Always. ... It's there 24-7. I'd almost say 28-7, [chuckling] ... Like no matter what you do, every time I gotta get up, I got to be careful.

The theme includes three sub-themes, *Fearing a Situation*, *Anticipating Problems*, and *Revealing the Secret*.

Fearing a Situation. Six participants described the sub-theme *Fearing a Situation* or worry about an uncomfortable or embarrassing situation occurring. Participants had no control over the behaviour of the ostomy, which affected them emotionally and psychologically. There was a constant worry or feeling of “*not knowing*”. Daphne explained, “*It kinda has a mind of its own ... you never know. ... [Is] it going to start doing something when you're halfway through? ... Like [you never know] what you're gonna be faced with.*” Daphne expanded:

It's always that not knowing, 'cause you could end up with diarrhea or [something else]. So you're always in this state of uncomfortableness almost because ... you can't count on it. [Chuckling] It's not your buddy, you know what I mean! [Laughing] Can't say, 'Be good!' if it misbehaves itself.

As a result, participants began to prepare for possible problems. Emma explained:

Now I double think things. ... I worry if I get out and if I have to go to the bathroom, then how do I empty this and all that. Like in a public place? I'm okay at home, and I'm okay at other people's houses that I know ... [but] a public place I'm still kind of struggling with that. 'Cause I rinse it with solution and stuff so that it won't smell. ... But when you're out, you don't have that solution.

Participants also worried about ostomy output and managing output. Daphne shared, *“[I was] taking the clip off ... to empty it and I lost grip on it and ... everything went all over the floor! [Chuckling] ... It was distasteful and unpleasant.”* In addition to spillages, participants worried about appliance failures causing leaks, Daniel explained, *“Somehow it’ll pressurize [with gas] or whatever and you’ll end up with a leak. That’s the biggest worry ... Is the leaking or something going wrong.”* Odours and noises were also on their mind. Alexis explained, *“It’s not only odours you’re guarding against, but you’re also guarding against gases and stuff.”* Thus, the lack of control over the unpredictable behaviour of the ostomy created fear of a situation occurring.

Anticipating Problems. The sub-theme *Anticipating Problems* refers to minimizing the risk of an uncomfortable or embarrassing situation from occurring by preparing ahead of time and/or deliberately adjusting their activities. Seven participants shared examples of how they anticipated problems during the interview and one during member checks. Mandi described:

I never got it so it was kind of, so it wouldn’t stop going ... And there was never any rhyme or reason to it. ... The thing tried to sputter all day. And I tried eating at very specific times to figure out what kind of a time delay do I get? [Laughing] The only thing I found is if I had to go out, or if I had to go to a meeting at work, I would not eat, and [would] take [an antidiarrheal medication]; which I’m sure is not very good for you. But that would kinda get me through whatever I had to do.

When preparing was not enough to minimize risks, participants deliberately adjusted their lifestyle. For Daniel, the adjustment was drastic, and also related to

his poor dexterity following cancer treatments and inability to visualize the stoma due to its location without using a mirror; these in turn resulted in his inability to change his appliance independently. Daniel elaborated:

I only take a shower once a week. Because I'll take it just before [my home care nurse will] come to change all that. Because I just don't want to be in the situation ... they say that you can take a shower every few days or so, but what happens if it comes off?! And then you're standing there in the shower. ... It's gone! And you've got the stoma thing stickin' out there and it's an involuntary muscle. ... So it just keeps pumping things out whenever it feels like! [Chuckling] ... I don't want to get in that situation, so I prevent it by not doing it. So, basically you end up washing in the sink all the time.

Revealing the Secret. The sub-theme *Revealing the Secret* is defined as the comfort level that accompanies the disclosure of the ostomy surgery and/or cancer diagnosis to others. Eight participants discussed the sub-theme during their interview and another during interviews for member checks. Participants' described how their level of comfort varied, and was determined by the relationship they had with the audience and their potential reaction, the environment and participants' circumstances, and personal perspectives. They described how the nature of the ostomy challenged attempts to safeguard their secret and how they adjusted their lives to maintain this secret.

Level of comfort with disclosing the surgery and/or cancer diagnosis to others varied. Some participants preferred privacy, while others felt comfortable sharing their situation with others. For example, for Andrew there was no need to keep his cancer diagnosis private, explaining, *"I mean it's nothing to be ashamed of. It's*

nothing I did to get it. What's the big deal ... about ... hiding it?" On the contrary, Olivia preferred discretion, where with other than select family members; she *"didn't want anybody to know about the cancer,"* although when disclosure focused on the surgery, her comfort level changed and she stated, *"I didn't have any problem with [sharing] the surgical part"*. Disclosure about certain aspects was acceptable, but not others as Emma illustrated when she shared:

Well they know I'm going through chemo. And my friends all know that I had bowel surgery, but there's only one who really questioned me on it. ... So she said to me, 'Okay, do you have this? Do you have that? And what about this? What about that?' So I told her [about the ostomy]. And then after I told her I thought, 'Huh, shit! It really isn't her business.

For Daniel, he felt comfortable with disclosure, declaring, *"I find it better to be straight out and forward or whatever. ... And tell people that this is the situation and I'm living with and have to live with."* However, for Samuel, keeping his ostomy surgery private was preferred, claiming, *"Most people don't know. I don't tell them."* Similarly, for Mandi, keeping the surgery private was of the utmost importance, asserting, *"I would not talk about this to anyone 'til you talked to the patient and kind of see what their wishes are. Some people I guess it doesn't bother them and they're fine. ... I was not one."*

The audience and strength of the relationship determined the level of comfort participants had about revealing their secret. For instance, Olivia stated, *"The only people that I wanted to know were ... [partner], my sister, and her husband"*. Daphne added:

I don't want to tell necessarily ... anybody my story. Like if I met somebody I haven't seen for a long time, [they] didn't know what had been going on with me and they ask me how I was, I'd say, 'Fine.'

Disclosure was also dependent on the audience's potential reaction. Emma elaborated on her experience with an ostomy support group, detailing, *"It was kind of an area where you can make fun of yourself, but you're not really making fun of yourself. ...you can do that there because you know no one's being critical of you or anything."* For Olivia, the revelation of a cancer diagnosis at work risked jeopardizing business, explaining, *"I've certainly seen what happens to others in the workplace if it's known you have cancer. The contracts dry up, [and] your contacts die up."*

The environment and particular circumstances surrounding the revelation also affected participants' comfort with revealing the ostomy. For example, Olivia revealed, *"I was worried about going on the airlines ... I wasn't fancying the idea of having anybody check me over."* For Samuel, he felt comfortable with letting his son know about a leak, but uncomfortable with letting his co-worker know, despite his co-worker already knowing about his ostomies. Samuel explained:

I didn't want to tell him [referring to son] because the other guy [referring to co-worker] was staring! [Chuckling] ... something like that [referring to his ostomy appliance leaking] I just couldn't tell the other guys. ... [but he] knows I have them too, eh [referring to ostomies]. Because I told him, I said, 'I have them ...'

Samuel's story also illustrated how the uncontrollable nature of the ostomy made keeping the secret difficult because its constant activity quickly changed circumstances and participants had to be quick to react and protect their secret. For

one participant, change in comfort level coincided with the change in his ostomy status; Daniel explained, “... *I do [feel comfortable with telling others] now! Because ... It's a no choice [since the ostomy is now permanent].*”

Revelation was also dependent on participants' personal perspective. For Daphne, the idea of involving others was unnecessary, stating, “*People have their own stuff; they don't need to hear all your nonsense.*” For Andrew however, disclosure about his cancer was therapeutic, claiming, “*I know other people sharing has helped me out.*”

Having a *level of comfort* suggests having a limit on one's ability to tolerate discomfort. For two individuals, preserving their *level of comfort* required adjusting their life. For Mandi, keeping the ostomy a secret while at work required carrying coffee or papers to help mask leaks or noises, as well as arranging to work from home. For Olivia, keeping the cancer diagnosis a secret while undergoing chemotherapy meant having to rearrange her work schedule around her treatment days. Preserving one's level of comfort in public also required adjustments. Mandi explained, “*I really just kind of went a couple [of] hours from home, or go somewhere where the people didn't know it was me [referring to ostomy].*”

When participants' were unable to preserve their level of comfort, they were left to “*struggle with an audience*”. For Mandi, the loss of privacy incurred a loss of dignity. She explained:

I truly thought any sense of dignity was totally [lost]. ... if you could kind of keep it ... within the people you live with ... it would have been better. But when it gets beyond that; I felt like I had to struggle with an audience. ... And you didn't know who knew, and who didn't know ...

Three participants shared how their significant other had shared their secret with others despite their request for privacy. In one instance, this added intense stress on the marriage. Consequently, the disclosure to one individual risked the disclosure to others. For example Alexis stated, *“They’re probably gettin’ feedback from the others too. Don’t ask her to come more than two [hours] ... It’s awkward or something like that. ...everybody understands.”* Participants had to contend with the reaction of others once their secret was revealed (whether or not by intention).

Daniel shared:

Like my friends know that I have an ileostomy. ... So if I just suddenly have to get up and go or whatever, they understand. But I mean it’s a matter of explaining it to people too though. I mean with a fresh crowd or something, they’ll probably think there’s something wrong with ya. ... Because you haven’t told them.

Participants also had to cope with unwanted attention in public as well as reactions from their family and friends, which was particularly difficult for those living in small towns. Emma shared how one of her daughter’s reacted to the activity of her ostomy in public:

We were at a store and I was paying for something and all of a sudden I started making all these noises and she [referring to daughter] left me! [Laughing] She just walked to the farthest door. ... I said, ‘Excuse me’ to the sales clerk. She said, ‘Oh! It doesn’t [matter] ... That’s okay’

Disclosure also meant potentially being *“overwhelmed by people asking how you are and wanting updates”*, as Olivia explained. In other cases, disclosure meant being treated differently as Emma illustrated:

I think people are still careful [of] what ... they say to me. ... I know when they talk to me and somebody has died, and I say, 'Well what did they die of?' And then if it's cancer, they kind of hum-and-ha and say, 'Well, they weren't feeling well for a while.' I'd say, 'Ya; but what did they die of?' And then I know it's probably cancer because they don't want to tell me.

Being treated differently also meant having people question your abilities, particularly at work as Samuel shared, *"They think I can't do what I used to do ... Well they treat me like if I was a sick person ... I can't do what I can do. ... maybe there's rumours get around that you're dying."*

The major theme *Always on my Mind* describes how participants' constant awareness of the ostomy impacted them emotionally and psychosocially. The presence of the ostomy and cancer diagnosis affected participants' emotions, where the nature of the ostomy created fear, which participants managed by deliberately adjusting their way of life. Past experiences helped them to learn which strategies were most effective. Participants had to manage their level of comfort when choosing to disclose their situation to others. When control over who knew and who didn't know was lost, preservation of their level of comfort was lost and participants were left to deal with worries about their audience's reaction and the consequences of disclosure on their lives. Nonetheless, despite the consequences that the ostomy and cancer diagnosis had on their lives, participants endeavoured to move forward with their changed life.

Moving Towards Independence

The major theme *Moving Towards Independence* is defined as the progression towards being self-sufficient. With the help of expert guidance, over

time, participants learned how to manage their ostomy and to eventually regain their independence, accepting their ostomy as a means to survive, living positively, and moving forward. The theme consists of two sub-themes, *Learning to Manage Independently* and *Getting on with Life*. It was described by all participants.

Olivia illustrated the theme when she expressed, “*So then I was at home with this pouch thingy. Hell! What do I do now?!*” When participants first arrived home, they had to manage their ostomy appliance independently. Education on how to manage the ostomy appliance began prior to hospital discharge by hospital staff nurses and/or ET nurses. In some cases, learning focused on how to empty the pouch, while learning how to change the appliance system occurred at home. In other cases however, both topics were addressed while in hospital prior to discharge home.

Learning to Manage Independently. The sub-theme *Learning to Manage Independently* refers to the content and quality of knowledge participants received from professional resources to become self-sufficient in their ostomy care, and was described by all participants. Healthcare professionals available to participants throughout their transition experience included physicians and nurses, such as ET nurses and home care nurses. Participants described how home care nurses were instrumental in helping them learn how to become independent with their ostomy care, how they and ostomy experts in the community helped them to manage problems, and how inability to become self-sufficient resulted in ongoing dependence on professional resources.

For some participants, in general, the time taken by physicians and nurses to answer questions was helpful, but for some, physicians provided vague or

insufficient information regarding the ostomy. Interestingly, for some participants, the hospital ET nurse was particularly unhelpful with learning how to care for the ostomy independently. Mandi stated, *“There was [a] nurse right in the hospital that kind of specialized in it too. I didn’t find her terribly helpful,”* but did not explain why. For her, the home care nurse was more helpful. In Emma’s case, her time with the hospital ET nurse was unhelpful because of distractions from the ET nurse’s beeper and disruptions from other healthcare professionals. Conversely, Olivia stated, *“I had had a good appointment with the hospital ostomy nurse [preoperatively],”* and added that the internet was also helpful.

Regardless of the education received while in hospital, mastery of the skills required to manage the ostomy appliance occurred at home with the assistance of home care nurses and home care ET nurses. Alexis explained:

The hospital [gives you] a brief synopsis ... [but the] hands on wasn’t [there]. ... The real people that taught me was the [home care] nurses. They did a beautiful job! ... They did hands on, and showed me, and made me practice with them after. So I became quite adept at ... helping myself.

The ostomy is always active and participants have no control over its activity. Thus, mastering the skills to manage the ostomy appliance was imperative to gaining independence. Daphne explained, *“I’ve been able to be independent as far as it goes [referring to her ostomy care]. ... Whether you want to do it or not is another story; but what are your choices? ... You can’t ignore it [laughing].”* Andrew further illustrated how self-sufficiency in ostomy care facilitated independence:

[My wife] went over the material ... with me ... But I said, 'I can handle this. ... I should be able to do it' 'Cause I said if we're out some place, I'm not expecting you to follow me into a non-gender ... washroom.

Learning to manage the ostomy independently required learning how to problem solve and make decisions related to one's specific ostomy care needs. For example, one challenge shared by three participants involved determining the most appropriate appliance system (minimum includes a flange and pouch). As Craig explained, *"Sometimes one is handier than the other."* Systems needed to coincide with participants' lifestyle, as Daniel explained, *"The smaller ones are better for me because of being active. If you have a much bigger ring [referring to flange opening] ... you have more [of a] tendency to make it loose."* An appropriate system was also necessary to accommodate stoma size and shape, and to prevent and manage problems, such as leaks, a problem shared by five participants. Mandi stated, *"It wouldn't [stop leaking] ... I think the problem was the stoma didn't stick out much. It was kind of recessed."* Systems also needed to coincide with body shape and stoma. Daphne laughed as she detailed her experience:

At some point my stoma got bigger. ... the flange that I was wearing before didn't fit [anymore] ... And I was faced with ... trying to squeeze ... a tiny hole [over it] ... [I] squeezed it on and thought, 'Oh my gawd. What am I going to do now?' ... it's not like you have something in the drawer that you could ... make fit.

Participants had to learn how to manipulate the appliance which included emptying and cleaning the pouch. Andrew shared:

Cleaning the bag out ... doesn't seem to go quite as well as it does on the DVD. [Laughing] ... So far I haven't had any problems with it other than I find it takes me maybe half-an-hour ... when I go to empty the bag. To get it clean enough.

Another challenge shared by three participants involved changing the appliance when the stoma was visible only with a mirror due to its location. Craig explained:

The thing I have a bit of a problem with is replacing the flange. To make sure that it's straight. ... [and that] the stoma's right in the centre. And of course you do it with a mirror it's not always that easy.

One participant, Emma, had been relying on her husband to change her ostomy appliance since her hospital discharge. She could empty her appliance, but like Craig, she also had difficulty coordinating her appliance changes with a mirror. However, she stated, *"I know I will do it eventually,"* indicating a desire to be independent. For Daniel, achieving independence was impossible because chemotherapy affected his fingers and required home care nurses to change his appliance weekly. Like Emma, although he knew the process of how to change the appliance, he could not do so independently. Although the level of independence achieved amongst participants was mixed, they all strived to achieve it.

When participants were unable to solve ostomy management problems on their own, they turned to resources such as home care nurses (including home care ET nurses) and ostomy experts from ostomy supply companies. Daphne shared:

They [referring to home care] had to have an ostomy nurse [referring to home care ET nurse] come in, like specifically [for me]. Because I was newest with the ostomy and they wanted [to know] if I had any questions or anything to go

over ... if you have no problems then ... they don't send them back. ...
Because the regular [home care] nurses that come, they're also trained ...
But a lot of the ostomy supply places have people ... that'll answer your
questions [too]. ... they have specialists there that'll get on the phone with
you ... and answer your questions if you have any problems.

Despite the availability of expert guidance, participants who were unable to manage their appliance independently had to rely on others for assistance with their ostomy care such as family and community resources. Relying on community resources limited independence because one had to request for assistance and wait for a response, as Daniel revealed:

I woke up in the morning and I thought, 'Gee, I feel kind of different ...'
[Chuckling] ... it had opened up during the night. ... So I put an emergency
call into [home care] and they sent someone over. But I mean you have a
four, five, six hour wait

Getting on with Life. The sub-theme *Getting on with Life* is defined as accepting the ostomy and cancer diagnosis and carrying on with everyday activities. All participants discussed experiences related to the sub-theme, which captures the psychological aspect of how participants conveyed an unenthusiastic acceptance and positive attitude to moving forward with life. Emma described the sub-theme saying:

If you don't have this done, your other alternative is you're dead. ... 'what was
my choice? Either this or I'm gone.' ... *I think you have to realize that and*
think, 'Okay, you have to get used to it because it saved your life and you're
going to be all right'

Participants unenthusiastically acknowledged and accepted the ostomy, which was driven by an understanding of the reason for its existence, cancer survival. Refusing the surgery meant choosing death, which Craig highlighted when he said, *"I knew that it was either accept that [surgery] or ... it was coming to an end."* Participants were averse to the ostomy surgery because the thought of living with an ostomy was a *"nightmare"* they did not want to live. Daphne explained, *"This was probably my biggest nightmare. ... like the worst thing that could ever happen to you. ... to me [it] seemed like, 'Oh my gawd! That would be terrible having to deal with that'".* Nonetheless, ostomy surgery was necessary to survive, *"it had to be done"* emphasized Samuel, *"The surgery, all that stuff; it had to be done"*. He elaborated:

... I had been told that I had as much as two weeks to live! ... Well, if I didn't get the surgery, he said I woulda been dead ... Okay, it's over! [Laughing] ... I said, 'It has to be done. It has to be done.' ... [At first] I was [against it]. It took me [a] long time ... [but] I had to because you couldn't move your bowels or anything... The choice [was death or an ostomy].

Participants underwent surgery and *"accepted it"* as Craig explained:

I accepted it. From the moment I was told I would have to do the surgery I said, 'Fine.' It's gotta to be done. Tell me when. Accept whatever it means. And that's it. ... Whatever it needed, I'm gonna do it, and then live with it.

In spite of these unknowns, participants maintained a *"positive attitude"* as illustrated by Andrew who said, *"Well, I guess that's the way life is." ... There's no real way of knowing. ... things ... show up ... that's the way life went. So let's try and keep a positive attitude,"* continuing, *"This is what's in our hands so let's deal with it*

and exercise our faith in God.” Participants’ positive attitude helped them continue living their life “day-to-day”. Daniel elaborated:

Keep a positive attitude. ... If you start thinking about stuff that’s going to happen or what might happen or all the changes, you can beat yourself to death with that. ... So, with a positive attitude, you just live ... day-to-day.

Participants’ positive attitude demonstrated an internal, motivating force to continue living their life; a certain “willpower” and will to fight, to survive. Samuel clarified, “You got to have willpower ... And don’t give up. You just can’t give up ... You just keep fightin’.”

Participants were averse to ostomy surgery. Nonetheless, they did what they had to do. Daphne explained:

I just sort of do what I have to do. I mean it’s not pleasant. ... You’re faced with ... something that you have to get used to; get accustomed to. ... But I mean it’s not pleasant. It’s like you’re up and personal with your crap.

[Laughing]

Participants approached their situation with a “have to” mentality. Daniel said, “You’ve just to live with it”, stressing that there was a need to “have to adjust”. Samuel explained, “There’s ups and downs about it, but you have to adjust to it. Like, you just have to adjust and whatever. And that’s it.” Following their surgery, participants recognized a call to “start dealing with life”, as Emma explained, “I think it’s just that it’s a shock, and then you have to get over that shock and start dealing with life and stuff.” For some, the “have to” mentality was motivated by their temporary ostomy status. Mandi explained:

... it was kind of a double edge sword there. 'Cause I think I would have been really frustrated with the chemo being sick all the time. And I found I kept saying, 'You know what, you wanna get rid of this [ostomy], you gotta put up with this.'

For some participants who were waiting for their reversal surgery to be confirmed however, getting on with life was at a standstill as their future was unknown. Alexis shared, *"This being terribly [underweight] is ... not only making a procrastinated thing about my [ostomy reversal] operation. ... It's stopping me from moving ahead in more ways than one."*

The major theme *Moving Towards Independence* highlights participants' forward movement and adjustment to living a changed life. With the help of home care nurses and ostomy experts in the community, they slowly increased their knowledge and learned the physical skills necessary to manage their ostomy, which facilitated their independence. They also learned psychologically to accept the ostomy as a means to surviving their cancer. With that in mind, they faced their situation with a positive attitude and carried on with living their new life; however, they did so with assistance.

I'm not Alone

The major theme *I'm not Alone* is defined as the supportive resources available to participants and their families following participants' ostomy surgery due to cancer. All participants described the theme, which includes two sub-themes, *Being Supported* and *Willingness to be Helped*. Participants recognized that they were "lucky" and were "thankful" for the support they received, acknowledging its positive result on their recovery. Emma emphasized:

I know how lucky I am because those other people have no one. ... it makes you thankful for what you have. Because I don't [know] what I would do if I was alone. I don't know what people do in that case.

Being Supported. The sub-theme *Being Supported* is defined as the help participants receive from others. It was described by all participants. Participants stressed how invaluable their families, friends, coworkers, neighbours, home care nurses, and support groups were with helping to complete practical and physical tasks, and providing psychological and emotional support throughout their recovery following ostomy surgery due to cancer.

From the moment participants arrived home, they received practical support from their families. For example, Craig described how his wife helped by preparing meals after his discharge from hospital. Similarly, Emma stated, *"The kids did the grocery shopping."* Due to the cancer diagnosis, participants may have undergone cancer treatments. As such, assistance with driving to and from medical appointments and cancer treatments was yet another example of how families supported participants with completing physical tasks. Emma explained, *"The girls [referring to daughters] all take turns bringing me to chemo. ... They'll drive me in. They'll sit there with me"*. For Andrew, volunteer drivers helped him get to and from appointments and treatments.

Participants felt that recovering alone *"would have been pretty tough"*. Craig elaborated on how his wife helped him recover:

I don't know what I would have done without her. It would have been pretty tough I think. I'm not sure that I could have done it. Even after four or five days you don't move very well. ... So here I didn't have to. Only when I was

ready. So I think it worked good. So I think anybody who doesn't have a wife there or somebody else to look after them, they'd be [in] bad shape I think.

Family, friends, coworkers, and neighbours were also supportive and understanding.

Daphne described her experience:

Like they'll call and say, 'Is there anything you need? Do you need to go anywhere? If you do, let me know ...' I know [that] if I need anybody to do anything for me then they would ... 'Cause people have been really nice.

For one participant, support from his community was overwhelming. Andrew shared:

I have an outdoor furnace. ... I burn wood with it. ... I had wood sitting there, and I got sick ... [Son #2] come over and he cuts some. My brother-in-law come[s] over and he cut some. ... Well then, [Brother-in-law] ... put together a work bee ... 20 guys showed up to cut and split wood. ... ten ladies they had food and most men came to help serve it. One employer, who he has three guys... he sent out here ... he said you're paid 'til [noon] then. Well they stayed, 'til 3:00. By 3:00 everything was done.

Families offered a “tremendous amount of support” and helped to keep participants “buoyant” as Alexis explained:

I got a tremendous amount of support. I think that maybe kept me buoyant. ... it's very hard to feel sorry for yourself when everybody's running ... rooting for you. ... To do that, you feel like you're really spoiling for attention or something. ... What do you have to feel sorry about when everybody is in your corner?

Reassurance from other patients with cancer was also helpful for one individual because it created peer support. Emma explained:

I know not to compare myself ... but we chat about ... the numbness ... I have a comrade kinda thing ... to have somebody to say, 'What the hell is this?' And she's saying, 'Ya. I had that two days ago. You'll be fine and stuff.'

In addition to helping patients learn how to manage their ostomies, home care nurses also helped patients “to adjust”. Alexis elaborated:

The nurses were marvellous I find, in helping me to adjust. ... The [home care] ones were to me, the ones that really taught me how to [get] the hang of it. Because it could be overwhelming; so much at a time.

For one individual, Emma, the support she received from an ostomy support group was informative as well as supportive, as it allowed her to meet other patients with an ostomy. She shared:

It was really, really interesting. I mean there's people there who have had them for 35 years. ... And they showed 'em a movie of different products that you can use. ... So, this film was kinda showing these things. But it also showed people with different stomas as well.

Willingness to be Helped. The sub-theme *Willingness to be Helped* is defined as the patients' openness for asking or receiving assistance from others. The idea of asking for or receiving help was “a hard thing” to do. Although participants were thankful for the support they had received, at least four participants voiced their reluctance to receive or ask for help. Participants explained their emotional discomfort; they were not accustomed to asking for and receiving help, although they had supportive resources available to them throughout their transition. Daphne elaborated, “*I don't ask for help. So that's been a hard thing too, is being able or willing to have people help you. I'm not good with that.*” Participants now had

“to rely on people” and therefore ask for help. For those who “would do anything for anybody else,” the idea of asking for and receiving help was uncomfortable. Emma explained:

I never had to rely on people so much ... I know there's drivers that will take you to chemo and stuff like that, but I'm not comfortable with that. I'm not comfortable with asking other people to do things. I would do anything for anybody else. [Chuckling] ... But I still have trouble; I can't ask somebody else to do that.

For Alexis, receiving help made her “feel guilty” at the thought of creating burden on the other person. She explained:

My cousin was ... bringing soup ... the other one cheese. [Laughing] ... you're trying to be grateful ... My sister was sending [immune supplements]. ... For months, and I just told her, 'Stop! I'm beginning to feel guilty.' Because she's no money person. This thing is like \$135 or something. ... you don't want to transfer the problem to her now. ... You're standing up and she's falling down.

For Alexis the support she received from her family eventually turned into pressure to move closer to them since she lived alone and out of town. She shared:

Just in case at any time I need something ... there's nobody ... [here] ... to ... help me. ... It is a decision I have put off forever. I want to stay in [the city]. My brother ... was persecuting [me] every phone call. 'Cause he's ready to find a place [closer to them.] ... They're feeling guilty they're too far to help.

The major theme *I'm not Alone* described the value of the support network throughout participants' transition. It also highlighted how some participants had to learn to rely on their support network as they transitioned to living their new life.

Chapter 5 – Discussion

The aim of this study was to describe the lived experience of patients with an ostomy due to cancer following hospital discharge. The specific objectives were to describe the experience and care needs of these patients as well as to describe the factors that facilitate or impede meeting their care needs. This chapter begins with an overview of the findings describing the experience and care needs of participants. A discussion of facilitators and barriers to meeting participants' care needs, implications for nursing, and study limitations and strengths will then follow.

Overview of the Findings: The Lived Experience & Care Needs of Patients

This is the first known Canadian study to describe the lived experience of patients in the midst of transitioning to living life with an ostomy due to cancer within their first three years following hospital discharge. This study details their comprehensive care needs, and gives an indication of how meeting these care needs were facilitated and impeded during the transition process. The essence of the lived experience of participants experiencing this process was described as *Adjusting to a New Way of Living*. The essence was represented by four major themes; *Some Things are Different*, *Always on my Mind*, *Moving Towards Independence*, and *I'm not Alone*.

The major theme *Some Things are Different* described how participants' lives were forever altered following ostomy surgery due to cancer. Their new reality involved adjusting to financial implications related to ostomy supplies, and changes in their sense of self, physical being, lifestyle, and social and intimate relationships. Participants described how changes in one aspect of their life influenced another, and cancer treatments affected these changes further. Most of these findings are

consistent with other studies reporting that after ostomy surgery, patients experience financial challenges with regard to ostomy supplies (Grant et al., 2011; Haugen et al., 2006; Lynch et al., 2008; Sahay et al., 2000); and changes in self- and body-image (Annells, 2006; Brown & Randle, 2005; Persson & Hellström, 2002), leisure and daily activities (Andersson et al., 2010; Grant et al., 2011; Honkala & Berterö, 2009; Krouse et al., 2009; Lynch et al., 2008; Mitchell et al., 2007; Sahay et al., 2000), social interactions (Andersson et al., 2010; Annells, 2006; Mitchell et al., 2007; Persson & Hellström, 2002), and personal relationships including sexual intimacy (Çakmak, Aylaz, & Kuzu, 2010; Persson & Hellström, 2002). Interestingly, no other known study has described how cancer treatments additionally influence the changes that patients experience. In this study, participants described how cancer treatment side-effects further impacted changes in their diet and bowel routine, social life, daily activities, sexual intimacy, and financial expenses, suggesting that their experience of the ostomy could not be separated from their experience of cancer. This finding will be discussed further in the following section.

In the major theme, *Always on my Mind*, participants described how the uncontrollable nature of the ostomy compelled them to constantly prepare for the unexpected and continuously work to keep their secret (having an ostomy, cancer diagnosis) private. These results support the existing literature on the negative effect of ostomy output on patients' psychosocial and emotional wellbeing (Andersson et al., 2010; Annells, 2006; Mitchell et al., 2007; Persson & Hellström, 2002). However, findings in this study also highlighted how participants dealt with the consequences of their secret being revealed, sometimes by their significant other, without their agreement or consent, and the resulting impact on their transition experience.

The major theme *Moving Towards Independence* described how participants persevered despite all of these challenges to attain independence. They came to accept the ostomy surgery and its consequences as a means to survive their life threatening disease. With this realization, participants adopted a positive attitude and moved forward with living their new life. These findings are consistent with previous studies which have also noted that following ostomy surgery, patients take on a positive perspective of their colorectal cancer, viewing ostomy surgery as a means to survive (Andersson et al., 2010; Sahay et al., 2000). However, in some cases, when reversal surgery was not confirmed, moving forward with their life was at a standstill. In addition, results of this study described how with guidance from home care nurses and ostomy experts in the community, participants learned to become self-sufficient in their ostomy care, further revealing the value of the home care nurse in facilitating patients' transition following hospital discharge. Indeed, participants described how their autonomy in ostomy self-care and support network was instrumental in helping them to carry on with living their new life independently.

Participants described how the transition experience was made easier with the support of family, friends, coworkers, neighbours, home care nurses, and support groups in the major theme *I'm not Alone*. Participants described how their support network assisted with completing practical and physical tasks, and supported them psychologically and emotionally. However, for some participants, asking for and/or receiving help from others required more effort than for other participants.

In summary, all participants described a transition to a changed life that required that they achieve independence to meeting their comprehensive care

needs and adjust to always having their ostomy on their mind. Participants did not feel alone in their transition.

Meeting Care Needs: Facilitators and Barriers

In addition to the usual physical and informational supportive care needs described by participants in this study, participants also described practical, psychosocial, and emotional supportive care needs. Their care needs were described as interconnected, in which changes in one area influenced another. For example, participants described how changes in their social life were affected by changes in their diet and bowel routine. They explained how their care needs were addressed by home care nurses and participants' support network; while being impeded by cancer treatments, the role of the significant other in the participants' loss of privacy, funding for ostomy supplies, and temporary ostomy status.

Home care nurse. Home care nurses were described as facilitating participants' transition experience by meeting their care needs. These findings are consistent with other studies that underscore the significant role of home care nurses (Molassiotis et al., 2009; Setter, Corbett, & Neumiller, 2012; Stajduhar et al., 2011). For example, home care nurses play a role in determining access to and delivery of palliative home care services (Stajduhar et al., 2011), the delivery of home chemotherapy treatments (Molassiotis et al., 2009), and facilitating an optimal patient transition from hospital to home for medication management (Setter et al., 2012). Findings of this study indicate that home care nurses focused their care to address participants' informational and physical care needs specific to ostomy self-care. This focus is not surprising given the negative impact of poor peristomal integrity on the quality of life and surgical recovery of patients with an ostomy

(Agarwal & Ehrlich, 2010), and the association between ostomy self-care and positive adjustment to an ostomy (Marquis et al., 2003; Piwonka & Merino, 1999; Simmons et al., 2007). However, the findings also indicate that participants had psychosocial, emotional, and practical care needs as well. It is therefore important for home care nurses to be cognisant of the comprehensiveness of patients' care needs during a transition, and how their role, and the information and support that they provide can help to facilitate meeting these additional patient care needs. However, little research exists regarding their role in the care of patients with an ostomy despite acknowledgements of the value of home care following hospital discharge (RNAO, 2009; St-Cyr, 2002). Based on the results of this study, more research is needed to understand better how to optimize home care nurses' instrumental role in patients' transition experience.

Support network. Results of this study also indicate that participants' support network acted as a facilitator to meeting participants' care needs during the transition experience. This finding is consistent with previous studies that have also reported the positive influence of interpersonal relationships (Simmons et al., 2007) and significant others on patients' psychosocial adjustment to (Altschuler et al., 2009; Piwonka & Merino, 1999) and physical care of the ostomy (McMullen et al., 2011). However, such studies have included patients with an ostomy not due to cancer (Piwonka & Merino, 1999; Simmons et al., 2007), and findings from this study have highlighted that the experience of having both an ostomy and a cancer diagnosis are intertwined. Studies including only patients with an ostomy due to colorectal cancer have noted a negative to patients' adjustment to and/or physical care of the ostomy when receiving inadequate (including withdrawal of) support from

one's significant other (Altschuler et al., 2009) or caregiver (McMullen et al., 2011). Thus, the importance of the patients' support network on the transition experience needs to be acknowledged and assessed because failing to do so may risk neglecting patients' care needs. More research is needed in this area to appreciate better and to optimize the role of the support network on patients' transition experience.

Cancer treatments. Cancer treatments were described as a barrier to meeting participants' care needs in this study. Chemotherapy used for treating colorectal cancer is known to induce bowel changes and neuropathy (Gibson & Keefe, 2006; Grenon & Chan, 2009; Leung, 2011). In this study, cancer treatments affected the physical, psychosocial, and practical aspects of participants' lives, including sexual intimacy. The literature on the effect of cancer treatments on patients' transition to an ostomy is mixed. Other studies have either reported a negative consequence following hospital discharge (Beaver et al., 2010) or no consequence on patients' acceptance (Chao et al., 2010) or adjustment to an ostomy (Simmons et al., 2007). However, study participants of these studies have included a mix of patients, including those with colorectal cancer but not necessarily an ostomy (Beaver et al., 2010; Chao et al., 2010) and those with an ostomy but not necessarily one due to cancer (Simmons et al., 2007). On the other hand, a Canadian qualitative study noted that participants with colorectal cancer stated that *treatment* side-effects were a negative consequence of the cancer and treatment (Sahay et al., 2000). However, the researchers did not provide treatment specifics (e.g., chemotherapy, radiation) or details of the consequences, and almost half of their participants did not have an ostomy. Thus, it is difficult to appreciate how

cancer treatments affected patients' care needs as they transitioned to life with an ostomy, and more research is needed in this area.

Results of this study also suggest that cancer treatments mostly affected participants' social and physical care needs. Deficits in these areas are of particular importance given that social interaction and ostomy self-care management may be associated with positive adjustment (Piwonka & Merino, 1999; Simmons et al., 2007). Thus, the findings of this study are noteworthy because the time immediately following ostomy surgery has been previously shown to be a difficult period (Carlsson et al., 2010; Ito et al., 2012; Marquis et al., 2003; Pittman et al., 2009; Piwonka & Merino, 1999; RNAO, 2009), and also coincides with the learning of independent ostomy self-care and the scheduling of cancer treatments. Future exploration into the significance of these findings in this study may help to inform patients' decisions regarding cancer treatments, and to tailor better the care of those in transition and receiving cancer treatment.

Loss of privacy: The role of the significant other. In this study, participants worked hard to maintain privacy (ostomy surgery, cancer diagnosis). The participants' support network was a facilitator to meeting their care needs and included their significant other. However, the results also indicate that when the significant other failed to keep participants' situation private, the significant other become a barrier to meeting participants' care needs.

This is the first know study to describe how some participants' significant other breached their confidentiality and how this action affected them. The complex issues surrounding one's *decision* to disclose a cancer diagnosis (Williams & Kent, 1996) and ostomy (Frohlich, 2012) have been examined previously; however, in this

study, participants' sometimes lost control over this decision. In addition, these studies examined only one item of disclosure (cancer diagnosis, ostomy), whereas in this study, the experience of the ostomy and cancer diagnosis were interconnected, suggesting that disclosure is more complex for patients with an ostomy due to cancer. One earlier study described how patients' spouses felt lonely and had no one to talk to about their uncertainty and fears about the cancer because attention was focused on the patient, despite the ostomy having changed both of their lives (Persson et al., 2004). The findings of Persson et al.'s (2004) research suggest that perhaps participants' partners in this study breached confidentiality as a means to cope and adapt with the participants' situation; however, reasons for the breach in confidentiality were not explored.

Participants in this study described the importance of having a support network, including the invaluable support one receives from their significant other. Consequently, the loss of privacy due to non-consensual disclosure by a significant other may be detrimental for their relationship, and thus patients' transition. This finding adds to the current literature and stresses the need for including significant others and the family *throughout* the transition, supporting them as needed.

Funding for ostomy supplies. Ostomy supplies are funded on a provincial level in Canada, and inconsistencies in Ontario's Ministry of Health and Long-term Care (2012b) funding model for ostomy supplies appeared to be a barrier to meeting patients' practical care needs. In Ontario, government assistance for ostomy supplies may negatively affect certain patients (e.g., temporary ostomy status; retired or uninsured); while positively having an effect on others (e.g., permanent ostomy status; Ontario Works recipients). In 2010, the average age of retirement

was 62.1 years (Statistics Canada, 2013), while in 2012, half of those aged 70 years or older were expected to be newly diagnosed with colorectal cancer (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012); hence, the majority of newly diagnosed patients with colorectal cancer in 2012 could be retired. Participants in this study were younger than the 2012 expected age of colorectal cancer diagnosis, and about half of them were not working. Although patients with a permanent ostomy benefited from the Ministry of Health and Long-term Care's (2012b) Assistive Devices Program, at least five participants had a temporary ostomy at one point, which disqualified them from receiving government support under this program. There is limited information available on the number and status of ostomies, the average annual cost of supplies in Ontario and across Canada, effect of ostomy status on patient finances, and patient strategies used to offset costs within a Canadian context. Hence, findings of this study stress the importance of addressing this care need pre- and postoperatively, particularly since practical care needs regarding finances have the potential to be problematic beyond the period of transition. In addition, there is a need for further examination into the depth of this findings' impact on patients.

Temporary ostomy status. The designation of one's ostomy status as temporary implies that the ostomy will be reversed in the future. Findings indicate that some participants' ability to get on with living their life was impeded by their temporary ostomy status. As a result, temporary ostomy status was a barrier for some participants. It is difficult to predict if and when a temporary ostomy can be reversed, given potential complications associated with surgery for ostomy closure (e.g., anastomotic leakage; bleeding), as well as the time needed to recuperate from

the psychological and physical effects of surgery for ostomy creation (Taylor & Varma, 2012). A review of the literature found that the time to ostomy reversal was influenced by advanced age, post-operative treatment for cancer, stoma and surgical complications following surgery for ostomy creation, and type of stoma (e.g., loop ileostomy, sigmoid colostomy, double-barrel ostomy) (Taylor & Varma, 2012). A British study of patients who had undergone ostomy reversal surgery for various etiologies (n = 61, 44% return rate) found that 48% of respondents waited over six months for the reversal surgery. However, the study could not determine personal consequences associated with delays in undergoing reversal surgery. As a result, the optimal time to closure of a temporary ostomy remains unknown, and more research is needed. Healthcare professionals must therefore address the benefits and consequences of having an ostomy deemed temporary (e.g., risk for change of status from temporary to permanent if reversal surgery is not possible; financial implications) preoperatively to inform patient decisions regarding surgery. Factors associated with delays in reversal surgery should also be discussed to assist patients with coping during the waiting period.

Implications for Nursing Practice

The following section will discuss how findings of this study may influence, a) the role of the nurse in the transition experience, b) when, and how nursing assessments are conducted, and c) collaboration within an interprofessional care team.

Role of the nurse. The findings of this study suggest that nurses need to be cognisant of the significant role they have in patients' transition experience, in that the care they provide facilitates patients' transition and meeting of patients' care

needs. Participants described the involvement of hospital staff nurses, enterostomal (ET) nurses, and home care nurses. Similar to recommendations from ostomy care clinical guidelines (RNAO, 2009), findings of this study suggest that patients would benefit from a comprehensive approach to care. Care needs identified in this study reflect most of the need domains of the Supportive Care Framework (SCF) (i.e., psychological, emotional, spiritual, social, physical, practical, and informational) (Fitch, 2008a; Fitch, 2008b), providing evidence that it is an appropriate framework for conceptualizing care for patients transitioning to life with an ostomy. Thus, it may be a useful conceptual framework for nurses to assess these patients. The SCF has already been shown to be beneficial in caring for patients with lung cancer (Fitch & Steele, 2008).

Nursing assessment. Nurses should integrate ongoing assessment and evaluation of the need domains outlined in the SCF when caring for patients who are transitioning to life with an ostomy due to cancer following hospital discharge. Physical, emotional, psychological, social, practical, and informational need domains were identified in this study, with most of the participants' care focusing on their physical and informational care needs. However, participants required care for non-physical and non-informational needs as well. Thus, a comprehensive assessment of the need domains would allow nurses to assess all need domains, to identify specific care needs, and to tailor and evaluate interventions accordingly (Fitch, 2008a; Fitch, 2008b). Based on the findings of this study, Table 5.1 was created to summarize the link between need domains of the SCF and care needs identified in this study according to each major theme and sub-theme.

Table 5.1

Need Domain affected during Transition & Care Implications for Associated Care Needs

Major Theme		
Sub-theme	SCF Need Domain	Care Implications for Associated Care Needs
Some Things are Different		
Body Image Changes	Physical Emotional	Information and emotional support with physical and physiological changes.
Changes in Lifestyle	Physical Social Practical	Practical information and support on how to cope and adapt to physical, social, and practical changes in everyday living. Being cognisant of the impact of cancer treatment on lifestyle.
Changes in Being Intimate	Psychosocial	Information and psychological support with regaining intimacy, including during cancer treatments. Involvement of the significant other throughout care.
Affording the Ostomy	Practical	Information and support with financing supplies. Being cognisant of how ostomy status and appliance system can affect finances.
Always on my Mind		
Fearing a Situation	Psychosocial Emotional	Practical information and support with re-engaging in social interactions and managing anxieties. Being cognisant of the effect of cancer treatment on wellbeing. Involving and supporting the significant other and family throughout care.
Anticipating Problems		
Revealing the Secret		
Moving Towards Independence		
Learning to Manage Independently	Informational Physical	Education on and ongoing support (encouragement) with ostomy self-care management. Being cognisant of the impact of cancer treatment on wellbeing.
Getting on with Life	Psychological	Psychological support with accepting, and coping and adapting to the ostomy and cancer diagnosis. Assistance with maintaining a positive attitude.
I'm not Alone		
Being Supported	Physical Practical Psychological Emotional	Education, and psychological and emotional support to facilitate coping and adaption. Assistance with completing physical and practical tasks. Encouraging patients to ask for and accept help during recovery process, while still facilitating independence. Involving the significant other and family throughout care.
Willingness to be Helped	Emotional	

Although some participants described how their attendance at church changed, they described these changes as influenced by cancer treatment side-

effects (e.g., increased susceptibility to infections in public, fatigue) rather than to changes in their spirituality or existential existence. Furthermore, participants' perception of having to undergo ostomy surgery as a means to live was in line with coping rather than attaching an existential meaning to their life. Previous studies have also reported minimal patient discussion regarding spirituality following a diagnosis of colorectal cancer (with or without an ostomy) (Sahay et al., 2000) and ostomy surgery due to colorectal cancer (Grant et al., 2011). Nonetheless, it is important to identify and address patients' spiritual care needs (Fitch, 2008a; Fitch, 2008b); however, guidance to do so is limited, and further research is needed.

Facilitators and barriers have a significant influence to meeting these care needs, particularly patients' support network. Similar to the recommendations outlined in ostomy care clinical guidelines (RNAO, 2009), a comprehensive approach to care should therefore acknowledge the importance of ensuring patients' support network, particularly their significant other, be included *throughout* their transition. Nurses should discuss with their patients the important influence that their support network has on their recovery, and ask them for permission to include members of their support network in their care. By utilizing the SCF to complete a comprehensive assessment and evaluation of patients' care needs during a transition, nurses could help facilitate a healthy transition by using the information to tailor interventions appropriately, while being aware of the dynamic nature of care needs.

Ostomy care clinical guidelines recommend that education be provided to both patients and their families preoperatively (RNAO, 2009), and note that education delivered by ET nurses facilitate adjustment to the ostomy (Haugen et al.,

2006). Thus, nursing assessments of patients with a new ostomy should occur well before hospital discharge. There should be a focus on anticipating potential issues such as poor body image, difficulty with intimacy, knowledge deficits and challenges with practical living and cancer treatments, financial challenges, and loss of privacy. In addition, nurses should ensure that decisions regarding ostomy surgery address patients' financial situation, and cancer treatment plans should assess how side-effects may impact the transition to life with an ostomy due to cancer. Hence, nurses should conduct a comprehensive assessment with patients and their support network, and use the information gathered in conjunction with the expertise of an ET nurse to help identify potential issues and to inform patients' decisions prior to surgery, facilitating a healthy transition.

Interprofessional care team. Ostomy care clinical guidelines recommend an interprofessional team approach to care, where care plans include discussions with patients and their support network (RNAO, 2009). Interprofessional care is defined as “the provision of comprehensive health services to patients by multiple health caregivers who work collaboratively to deliver quality care within and across settings” (Interprofessional Care Strategic Implementation Committee, 2010, p. 1). Findings of this study described how healthcare professionals included physicians and nurses. Although overall participants felt that their questions were addressed by healthcare professionals, they also described how information from one healthcare professional regarding the ostomy was at times insufficient or less helpful when compared to another (e.g., physician versus home care nurse). An advanced practice nurse could work as a team leader to coordinate the care provided by an interprofessional team (e.g., social worker, physicians, pharmacists, oncology

specialists), utilizing each member's expertise to optimize care delivery (O'Connor, 2003). Based on reported interprofessional team challenges in palliative home care (Neergaard, Olesen, Jensen, & Sondergaard, 2010), to ensure optimal team work and care delivery, the team leader should work to distribute tasks amongst the team members, facilitate information sharing and team communication, encourage respect for each members' expertise, and acknowledge individual schedules when coordinating team meetings. Consequently, the team can help to inform patients and their support network throughout the transition, and support them in their care decisions.

ET nurses have been shown to expand the home care nurses' understanding of and self-assurance in the delivery of wound care (Baich et al., 2010). Since ET nurses' expertise also includes ostomy care, it follows that they would be beneficial in the home care nurses' understanding and delivery of ostomy care. Although at least two participants in this study described the hospital ET nurse as unhelpful, all participants in this study did not describe deficiencies in the care they received from home care nurses (including home care ET nurses). Moreover, this study examined the patient's perspective and did not examine the healthcare professional's perspective (i.e., ability to provide care within an organization or health care setting, knowledge and comfort with ostomy care and management). Current research suggests that home care nurses experience limited resources such as staffing and government funding (Armstrong-Stassen & Cameron, 2005; Forbes & Edge, 2009; Stajduhar et al., 2011). Findings of this study highlighted the important role of home care nurses in the patients' transition, particularly in re-establishing their independence. Thus, the advanced practice nurse team leader could also help to

optimize the delivery of home care by facilitating information exchange between ET nurses and home care nurses.

Implications for Nursing Education

The findings of this study described the comprehensive care needs of patients and the role nurses play in addressing these care needs. For example, home care nurses in this study were instrumental in helping participants master the skills necessary for ostomy self-care to enhance the move towards independence. Although not explored, one reason for this finding could be because the long-term contact between home care nurses and the participants allowed for the development of ostomy care skills. A study assessing knowledge gaps and services supporting patients with colorectal cancer reported that only 30% of the 19 staff nurses who responded to the study survey felt that they cared for enough patients with an ostomy to maintain their ostomy care skills, and 70% were worried about their patients' preparedness for ostomy self-care following hospital discharge (Gemmill, et al., 2011). For many student nurses and hospital staff nurses, contact with patients with an ostomy may be limited or frequent. Nonetheless, it is important that nurses appreciate patients' comprehensive care needs.

An effective educational approach includes a simulation lab where participants are asked to wear an ostomy appliance filled with pseudo-fecal matter for 24 hours and then to reflect on their ostomy experience (Reed, 2012). This would allow participants to understand better the experience of their patients. Findings of this study also highlighted that sensitive but necessary topics such as sexual intimacy were inadequately addressed for some participants. Another effective educational approach includes developing simulated learning activities to practice

addressing sensitive topics to patients, so that participants may develop confidence and patient teaching skills (Reed, 2012). Education should include developing skills that assess patient learning needs and readiness to learn, since patient education could occur preoperatively or postoperatively in a busy hospital environment where teaching time may be limited (Gemmill et al., 2011).

Given the importance of nurses in facilitating the transition of patients with an ostomy in this study, continuing education or staff orientation should also include increasing nurses' knowledge on the transition experience. For example, a mentorship program could be developed to pair advanced practice nurses and/or experts in transitional care with staff nurses, ET nurses, and home care nurses to enhance their understanding of the transition experience and the provision of supportive care during patients' transition from hospital to home. Such a program has been successful in education for interprofessional chronic illness care (Collins, Arenson, & Antony, 2008). The mentorship program curriculum could include education on a) understanding the concept of transition, b) how to assess the care needs of patients during a transition using the SCF, c) how to develop and tailor interventions accordingly, d) how to provide and evaluate interventions and strategies (e.g., to encourage positive attitudes in patients, to involve patients' support network in the care plan), and e) how to access resources and work within an interprofessional care team.

Implications for Future Research

There is a paucity of literature on the transition experience and care needed to facilitate a healthy transition for Canadian patients with an ostomy due to cancer following hospital discharge. Based on the results of this study, recommendations

for further research include; a) evaluating the effectiveness of the SCF in guiding the nursing care of patients with an ostomy due to cancer following hospital discharge based on the care needs presented in Table 5.1, b) exploring the confidentiality concerns between patients and their significant other and the implications on patients' healthy transition, c) identifying patient costs associated with ostomy surgery in Ontario to better inform patients' decision to undergo ostomy surgery (e.g., cost of supplies for those with no assistance from government funding or private insurance) and ethical implications, d) exploring the consequences of having a temporary ostomy on patient adjustment to an ostomy.

Limitations and Strengths of the Study

The transferability of the findings of this study is limited as the lived experience is individual and subjective, and may differ for patients who have an ostomy due to another etiology, live in different regions, or who have had their ostomy for more than three years. However, despite these limitations, results of the study highlighted several implications for nursing practice, education, and research. In addition, participants who volunteered for this study may have had more positive experiences and thus more willing to participate. Their willingness to participate allowed for a rich, in-depth account of the transition experience, thereby allowing for a detailed description of the experience and facilitating transferability. The experience may also differ for those from other cultures or races because the majority of participants were Caucasian. Purposive sampling allowed for a balanced mix of male and female perspectives from different ages, living settings and arrangements, employment statuses, and different stages of the transition

experience. Furthermore, credibility was ensured using member checks, where only minimal changes to the preliminary analysis were suggested.

Conclusion

Participants' lives were forever altered following ostomy surgery due to cancer. As participants transitioned to their new reality, it became apparent that they had to adjust to the financial implications related to ostomy supplies and changes in their sense of self, physical being, lifestyle, and social and intimate relationships. As time progressed, the interconnectedness of these changes and the added impact of cancer treatments became evident. Participants found themselves constantly preparing for the unexpected and working to guard their secret, and at times, having to deal with the consequences of having their secret revealed by the one person they trusted most. Yet, despite all of these challenges, participants continued to live on, accepting the ostomy surgery as a means to survive. With this insight, they carried on with living their lives positively, being guided and supported by home care nurses and community ostomy experts to become independent, and having their support network by their sides.

The in-depth description of the lived experience of patients transitioning to life with an ostomy due to cancer following hospital discharge in this study has contributed to the current literature on the transition process, experiences of patients with an ostomy, and the experiences of cancer. Participants' stories highlighted the comprehensiveness of their care needs, and detailed how their support networks and home care nurses helped to facilitate meeting these care needs, while cancer treatments, the role of their significant other in the loss of privacy, ostomy supply funding challenges, and temporary ostomy status were barriers.

Patients with an ostomy must undergo a profound change in their lives. Those having to live with the concurrent diagnosis of cancer, must learn to accept and adjust to a change that they view as both positively, because of the possibility of their cancer being cured, and negatively, because of the effect ostomy surgery has had on their lives. Patients also view the experience appreciatively, as it has offered them continued life, although forever altered. This study has provided a deeper understanding of this experience, and it is hoped that this understanding will help to benefit patients in similar circumstances in the future, and inspire nurses to be cognisant of how they themselves can significantly influence their patients' experience.

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Appendix A: Literature Search Procedure

Before Data Collection and Analysis	
Database	Literature Search Protocol
CINAHL	Search Terms: “ostomy” and “education” Search Limits: articles published between 1981 to 2009
	Search Terms: “ostomy”, “ostomate”, “ostomies”, “colostomy”, and “ileostomy” (each separated by the word “or”), with different combinations of “education”, “patient”, “patient education”, “cancer”, and “transition or coping”, using the word “and” Search Limits: peer reviewed articles, published between 1981 and 2009, English, adult population
	Search Terms: “ostomy”, “cancer”, and “transition or coping” (search results for each term were combined with the word “and”) Search Limits: peer reviewed articles in all journals, English, adult humans over 19 years
After Data Collection and Analysis	
Database	Literature Search Protocol
CINAHL	Search Terms: “ostomy” and “education” Search Limits: peer reviewed articles, published between 2009 and 2012, English, adult humans
	Search Terms: “ostomy”, “ostomate”, “ostomies”, “colostomy”, and “ileostomy” (each separated by the word “or”), with different combinations of “education”, “patient”, “patient education”, “cancer”, “transition”, and “transition or coping”, using the word “and” Search Limits: peer reviewed articles, published between 2009 and 2012, English, adult humans
	Search Terms: previous two search protocols combined with the terms “North America”, “North American”, “Canada”, “Canadian”, “United States”, and “American” (each separated by the word “or”) using the word “and” Search Limits: peer reviewed articles, English, adult humans Additional potentially relevant articles were retrieved electronically and non-electronically for further review.
	Search Terms: previous two search protocols combined with the terms “North America”, “North American”, “Canada”, “Canadian”, “United States”, and “American” (each separated by the word “or”) using the word “and” Search Limits: peer reviewed articles, English, adult humans Additional potentially relevant articles were retrieved electronically and non-electronically for further review.
Ovid Medline(R) Daily Update, University of Ottawa Full Text Journals@Ovid, and PsychINFO	Search Terms: “ostomy”, “cancer”, and “transition or coping” (search results for each term were combined with the word “and”) Search Limits: peer reviewed articles, published between 2009 and 2012, English, human(s)
	Search Terms: previous search protocol combined with individual search results of the terms “North America”, “North American”, “Canada”, “Canadian”, “United States”, and “American” using the word “and” Search Limits: peer reviewed articles, English, human(s) Additional potentially relevant articles were retrieved electronically and non-electronically for further review.

Appendix B: Telephone Script for Screening of Potential Participants by Study

Site Employee

The following telephone script was used by an employee of the Community Care Access Centre to contact potential patient candidates who were currently receiving services from the Community Care Access Centre at the time of the study as required by law. The purpose of this script was to assist the employee in determining candidacy by screening potential participants for study eligibility, notifying them of the study, and seeking their permission to be contacted by the principal investigator (PI). If the candidate agreed to be contacted by the PI, the PI then telephoned her/him at a later date to explain the details of the study and invite her/him to participate in the study. If the candidate chose to participate, the PI arranged a face-to-face interview with her/him at a mutually convenient time and place, or a telephone interview. **Under no circumstances was the employee of the Community Care Access Centre to seek the potential candidate's interest in the study or consent to participate.**

Basic Patient Information

Name of patient (Please Print): _____

Patent Gender (Retrieve information from name or voice.):

☐ Male ☐ Female

Telephone Conversation – Introduction

"Hello, my name is (your name). I am from the Community Care Access Centre. May I speak to (name of the patient) please?"

☐ Patient is home. Proceed to next section.

☐ Patient is not home. *"When is a better time to reach (name of the patient)?"*

☐ Time available Date: _____ Time: _____

*"Thank you. I will contact (name of the patient) then.
Have a good day."*

☐ Unsure. Call again. *"Thank you. Have a good day."*

Telephone Conversation – Reason for Calling

*"Hello, (name of the patient). My name is (your name). I am from the Community Care Access Centre. The reason I am calling, is because the Community Care Access Centre is participating in a study with the University of Ottawa. The study is [preliminarily] entitled, **"Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community"**. The purpose of the study is to learn more about the experiences of patients during their first year of adjusting to having an ostomy following cancer. I would*

like to ask you a few questions to find out if you would qualify for the study. Would you mind answering a few questions; it will only take about five minutes?"

☐ Yes "Thank you (name of the patient)."

(Proceed to next section, **Screening Questions...**)

☐ No "Is there a better time to call you back?"

☐ Yes "Wonderful (name of the patient). When would be a better time for me to call you back?"

Date: _____ Time: _____

"Thank you (name of the patient). I will contact you then. Have a good day."

☐ No "Thank you for your time (name of the patient). Have a good day."

Screening Questions for Appropriate Patient Participation

Proceed to ask the following questions in the order that they appear. If the patient does not hold one of the criteria, politely end the conversation with the following response:

"Thank you (name of the patient). Unfortunately you do not qualify for the study. Thank you for your time (name of the patient). Have a good day."

1. Do you understand and speak English, or have a family member who can assist you?

☐ Yes (Continue with Question #2.)

☐ No (Patient does not qualify. Politely end the conversation using the response provided.)

2. How old were you on your last birthday? _____

If the patient is 18 years or older, continue with Question #3.

If the patient is less than 18 years of age, the patient does not qualify for the study. Politely end the conversation using the response provided.

3. What was the reason for getting the ostomy?

☐ Cancer (Continue with Question #4.)

☐ Other than cancer. (Patient does not qualify. Politely end the conversation using the response provided.)

4. Do you have a permanent ostomy that passes stool (or feces) through an opening in your abdomen and into a pouch (or bag) without your control?

☐ Yes (Specify if known _____)

(Proceed with Question #5.)

NOTE: Patients must have a permanent ostomy that passes stool without their control to qualify for the study.

☐ No (e.g., temporary ostomy, passes urine, urostomy, kock pouch)

(Patient does not qualify. Politely end the conversation using the response provided.)

5. Have you had ostomy surgery and been discharged home within the last year?

☐ Yes (Proceed with Question #6.)

NOTE: Patients must have had both surgery and discharge home from the hospital within the last 12 months to qualify for the study.

☐ No (Patient does not qualify. Politely end the conversation using the response provided.)

6. *“(name of the patient) just one more questions. As I had mentioned earlier, the Community Care Access Centre is part of a study with the University of Ottawa. The study will attempt to gain a deeper understanding of the lived transitional experience of patients with an ostomy due to cancer within their first year home from the hospital. From what I have gathered, you qualify for the study. May I have your permission to give your name and contact information to the lead researcher so that she may invite you to participate?”*

☐ Yes (Proceed with Question #7.)

☐ No *“Thank you for your time (name of the patient). Have a good day.”*

7. *“Wonderful (name of the patient)!”*

(Retrieve the necessary information, as indicated below.)

Contact information:

Daytime Phone Number: _____

Evening Phone Number: _____

Best time to contact: _____

“Thank you for your time (name of the patient). The lead researcher, Liza Padilla, will contact you to formally invite you to participate in the study. Thank you again for your time. Have a good day!”

Appendix C: Telephone Script for First Contact with Principal Investigator

The following telephone script was used by the principal investigator (PI) to explain the details of the study to potential participants, and to invite them to participate in the study. When the candidate agreed to participate, the PI arranged a face-to-face interview at a mutually convenient time and place, or a telephone interview.

Basic Patient Information

Name of patient: _____

Patent Gender (Retrieve information from name or voice.):

☐ Male ☐ Female

Telephone Conversation – Reason for Calling

“Hello, my name is Liza Padilla. I am from the University of Ottawa. May I speak to (name of the patient) please?”

☐ Patient is home. Proceed to next section.

☐ Patient is not home. *“When is a better time to reach (name of the patient)?”*

☐ Time available Date: _____ Time: _____

*“Thank you. I will contact (name of the patient) then.
Have a good day.”*

☐ N/A *“Thank you. Have a good day.”*

Telephone Conversation – Introduction and permission to continue

“Hello, (name of the patient). My name is Liza Padilla, and I am from the University of Ottawa. The reason I am calling, is because (name of the recruiter from the Community Care Access Centre) from the Community Care Access Centre contacted you the other day to see if you qualified for a study that I am conducting. From what I understand you qualified for the study and you gave (name of the recruiter from the Community Care Access Centre) permission for me to call you. Do you remember that call?”

☐ Yes *“Great!”* (Proceed to next section.)

☐ No (Proceed to next section.)

☐ Please call back. I am busy at the moment.

“That’s not a problem. When is a better time for me to call you back?”

Date: _____ Time: _____

“Thank you (name of the patient). I will contact you then. Have a good day.”

Telephone Conversation – Purpose of Study and Permission to Participate

“Well, just to remind you (name of the patient), the name of the study is [preliminarily entitled] **“Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community”**. The purpose of the study is to learn more about the experiences of patients during their first year of adjusting to having an ostomy following cancer. Your participation will involve a face-to-face interview that would last about one hour. During the interview, I will ask you to describe your adjustment to life with an ostomy. The interview will be conducted by myself and will be audio recorded to help me collect the data. Your name and any other identifying information will be kept confidential, and your participation will not interfere with the services you currently receive from Community Care Access Centre. Also, you may volunteer to participate in a follow-up interview with me, where I will present the study’s overall preliminary findings to see how much they reflect your own experiences. This follow-up interview however, is optional and will only be conducted if you agree. Are you willing to participate in an interview? Shall I schedule an interview time?”

☐ Yes “Thank you (name of the patient).” (Proceed to next section.)

☐ Yes, but I would rather do a phone interview

“That is not a problem (name of the patient). We can set up a time and date for a telephone interview if you prefer. What I can do is send you a hard copy of the information letter and consent form for you to sign and mail back to me. Once I have received the signed consent form, I will contact you again to schedule an interview time.” (Proceed to next section.)

☐ No “Thank you for your time (name of the patient). Have a good day.”

Telephone Conversation – Scheduling Interview Time

☐ Yes “Wonderful (name of the patient)! (Retrieve the necessary information, as indicated below.)

Date: _____

Time: _____

Home Address and/or Interview Location:

Main Intersection (if applicable):

Contact information:

Daytime Phone Number: _____

Evening Phone Number: _____

Best time to contact: _____

“Great (name of the patient)! I’d like to give you my contact information in case you need to get a hold of me before our interview. Do you have a pen and paper handy? If you have any questions or concerns, you can contact me, Liza Padilla at [telephone number] or by email at [email address].”

*“**Thank you again for your time (name of the patient). I will bring a consent form for you to sign. Have a nice day.**”*

☐ No

“Thank you for your time (name of the patient). Have a good day.”

Telephone Conversation – Potential Questions Concerning the Study and Participation

The following section does not need to be discussed during the telephone conversation unless the potential participant asks one of the bolded prompt questions. In this case, the answer is found below each prompt and should therefore be relayed to the potential participant. After answering the question, the potential participant should be asked if s/he has anymore questions before ending the conversation.

What is the research question?

What is the lived transitional experience of patients with an ostomy due to cancer and their supportive care needs within their first year home following surgery?

What are the study objectives?

- 1. To describe and seek to further understand the experiences and the supportive care needs of ostomy patients following their discharge into the community.*
- 2. To identify the factors that facilitate meeting the supportive care needs of ostomy patients following their discharge into the community.*
- 3. To identify the factors that hinder meeting the supportive care needs of ostomy patients following their discharge into the community.*

Are there any adverse risks from participating?

“There are no foreseeable adverse risks for participating in the study.”

What if I change my mind about participating in the study?

“Your participation is voluntary and you may refuse to answer any question and/or withdraw from participating in the study at any time, with no effect to your services and care. Your participation will not be recorded in your patient records. If you choose to withdraw at any time during the study, you may either choose to have all data gathered up to the time of withdrawal included in the study or destroyed.”

Appendix D1: Participant Information Letter



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de la santé
École des sciences infirmières
University of Ottawa
Faculty of Health Sciences
School of Nursing

Dear Participant:

You are invited to participate in a Masters of Nursing thesis study [preliminarily] entitled **“Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community”**, conducted by Liza L. Padilla, BSc, BScN, MScN-PHCNP(C) student, RN, CGN(C), and her thesis supervisor Dr. Kathryn A. Smith Higuchi, RN, Associate Professor at the University of Ottawa, School of Nursing.

What does the study means to you?

We are interested in gaining a deeper understanding of the lived transitional experience of patients with an ostomy due to cancer and their supportive care needs during their first year home following surgery. Your participation in the study will help to expand knowledge on how to care for patients with an ostomy due to cancer.

You are invited to participate...

You will participate in one audio recorded interview of about one hour. You will be asked to describe your transition to life with an ostomy since your discharge from the hospital. Should you agree, you may also participate in a follow-up interview where you will be asked how well the overall study's preliminary findings reflect your own experiences. This interview will last about 30 to 45 minutes.

Are there any risks from participating?

Risks to participating in the study are minimal. There is a chance that you may get tired or upset from answering questions. If you get tired, the interviewer will give you a break or stop the interview and schedule another convenient time to finish it should you choose. If you are upset, she will advise you to call your community nurse and/or case manager to arrange for care as needed.

What if I change my mind about participating in the study?

Participation is voluntary and you may refuse to answer any questions and/or withdraw from participating in the study at any time, with no effect to your services and care. Your participation

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Faculty of Health Sciences

School of Nursing

will not be recorded in your patient records. If you choose to withdraw, you can choose either to have all data gathered up to the time of withdrawal included in the study or destroyed.

What about anonymity and confidentiality?

You will be assigned a code number so that your name and the names of any other people will not appear in the transcribed interview documents. There will only be one master list with your name and code number. It will be kept separate from the study data in a locked filing cabinet at the University of Ottawa Nursing Best Practice Research Centre. Only your code number will be used to identify your transcribed interviews. All results will be reported as grouped data. It will not be possible to identify you or your responses to specific questions in study reports. Direct quotes provided by participants may be used in summary reports; however, we will always remove any identifying information from the quotes.

The master list and study data will be stored for five years following study completion. After this time, the master list, paper data, audio data, and digital data will be destroyed.

What about patient privacy and confidentiality?

This research does not require access to personal health information through patient records. Published reports will not cite any identifying information regarding participants or the community program.

If you have any questions or concerns about this research, please contact the principal investigator for this project, Liza L. Padilla by email at [email address], or her Thesis Supervisor, Dr. Kathryn A. Smith Higuchi at [telephone number] or by email at [email address].

If you have questions about your rights as a research participant, please contact the Protocol Officer at the University of Ottawa's Ethical Office located at [address]. You may also contact the Protocol Officer by phone at [phone number] or by email at [email address].

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If you are interested in participating in this research, please complete the attached consent form. Thank you.

Appendix D2: Lettre de renseignements et formulaire de consentement pour les participant(e)s



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School of Nursing

Cher(e) participant(e):

Vous êtes invité(e) à participer à une étude pour soutenir une thèse de maîtrise en soins infirmiers intitulée [provisoirement] « **Vivre avec un appareil d'ostomie : L'expérience de patients cancéreux vivant dans la communauté,** » sous la gouverne de Liza L. Padilla, BSc., B.Sc.Inf., étudiante de la M.Sc.Inf., inf. aut., ISCG(C), et sa directrice de thèse, la docteure Kathryn A. Smith Higuchi, inf. aut., Professeure associée à l'Université d'Ottawa, École des sciences infirmières.

Que signifie l'étude pour vous?

Nous voulons obtenir une meilleure connaissance de l'expérience de patients vivant avec un appareil d'ostomie, dû à un cancer de même que de leurs besoins de soutien à domicile durant leur première année après la chirurgie. Votre participation à cette étude contribuera à améliorer nos connaissances quant aux soins à fournir aux patients avec un appareil d'ostomie dû à un cancer.

Vous êtes invité à participer...

Vous participerez à une entrevue enregistrée d'environ une heure. On vous demandera de décrire votre transition à vivre avec un appareil d'ostomie depuis votre congé de l'hôpital.

Si vous consentez, vous pouvez participer à une entrevue subséquente où on vous demandera si les résultats préliminaires de l'étude correspondent bien à l'expérience que vous avez vécue. Cette entrevue aura une durée de 30 à 45 minutes.

Quels sont les risques de cette étude?

Les risques liés à la participation à cette étude sont minimes. Il se peut que vous vous sentiez fatigué ou troublé par les questions posées. Si vous êtes fatigué, on vous offrira l'option d'une pause ou d'arrêter l'entrevue et reprendre à un autre moment propice. Si vous êtes troublé on vous recommandera de consulter votre infirmière communautaire ou votre gestionnaire de cas pour obtenir des soins au besoin.

Puis-je changer d'idée quant à ma participation?

Votre participation à l'étude est volontaire et vous pouvez refuser de répondre aux questions ou vous retirer de l'étude en tout temps sans influencer les soins ou les services que vous recevez. Votre



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participation ne sera pas notée dans les dossiers de patient. Si vous décidez de vous retirer de l'étude vous pouvez demander que toutes les données recueillies jusqu'à la date de votre retrait soient sauvegardées ou détruites.

Qu'en est-il de l'anonymat et de la confidentialité?

On vous assignera un code numérique et votre nom de même que celui des autres personnes impliquées n'apparaîtra pas dans les documents transcrits concernant l'entrevue. Il n'y aura qu'une seule liste maîtresse avec votre nom et numéro de code. Cette liste sera conservée séparément des autres documents concernant l'étude dans un classeur fermé à clé à l'Université d'Ottawa, Unité de recherche sur les pratiques exemplaires en soins infirmiers. Seul votre code numérique sera utilisé pour identifier la copie de l'entrevue. Tous les résultats seront rapportés en compilation. Certaines citations pourraient être utilisées dans des rapports sommaires mais l'identité des participants ne sera pas révélée. Il sera impossible de vous identifier ou d'identifier vos réponses à des questions spécifiques dans les rapports sur cette étude.

La liste maîtresse sera conservée pendant cinq ans suivant la fin de l'étude. Après cette période de temps, la liste maîtresse et autres documents, enregistrements et données digitales seront détruits.

Qu'en est-il des renseignements privés des patients et de la confidentialité?

Cette recherche ne nécessite pas l'accès aux dossiers médicaux des patients. Les rapports publiés ne mentionneront aucun renseignement concernant les participants ou le programme communautaire.

Si vous avez des questions ou inquiétudes concernant cette étude, veuillez communiquer avec Liza L. Padilla, l'investigateur principal pour le projet par courriel à [adresse courriel], ou sa directrice de thèse, la docteure Kathryn A. Smith Higuchi au [numéro de téléphone] ou par courriel à [adresse courriel].

Si vous avez des questions concernant vos droits comme participant(e) à une étude, veuillez communiquer avec l'agent du protocole de l'Université d'Ottawa, Subventions de recherche et déontologie, [adresse], ou par téléphone au [numéro de téléphone] ou par courriel à [adresse courriel].

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Si vous êtes intéressé(e) à participer à cette étude, veuillez compléter le formulaire de consentement ci-joint. Merci.

Appendix E1: Consent Form for Participant



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Transitioning to Life with a New Ostomy: The Experience of

Patients with Cancer in the Community

Consent for Study – Participant

I have read the letter of information, have had the nature of the study explained to me, and I agree to participate. All of my questions have been answered with satisfaction.

Name of Community Program (Please Print):

Participant:

Name (Please Print): _____

Signature: _____

Date: _____

Yes, I also consent to a follow-up interview if needed. ____ (initial)

Person Obtaining Consent:

Name: (Please Print): _____

Signature: _____

Date: _____

There are two copies of this consent form, one copy is for the researcher and one copy is for the participant. If you have requested a telephone interview, please mail a signed copy back to the PI in the stamped envelope provided.

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Appendix E2: Formulaire de consentement pour les participants



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Vivre avec un appareil d'ostomie: L'expérience de patients cancéreux vivant dans la communauté

Consentement à l'étude - Participant(e)

J'ai lu la lettre de renseignements, j'ai reçu l'explication de la nature de l'étude et, je consens à participer. J'ai reçu des réponses satisfaisantes à toutes mes questions.

Nom du programme communautaire (caractères d'imprimerie):

Participant(e):

Nom (caractères d'imprimerie): _____

Signature: _____

Date: _____

Oui, je consens à une entrevue subséquente,

au besoin. _____ (Initiales)

Personne qui obtient le consentement:

Nom (caractères d'imprimerie): _____

Signature: _____

Date: _____

Il y a deux copies de ce formulaire de consentement, une copie pour le chercheur et une pour le/la participant(e). Si vous avez demandé une entrevue par téléphone, veuillez envoyer une copie à l'investigateur principal pour le projet dans l'enveloppe affranchie, ci-jointe.

Appendix F: Interview Schedule

Introduction – Study Information Sheet and Consent

*“Hello, (name of the participant). Thank you for taking the time to speak with me. Let me reintroduce myself. My name is Liza Padilla. I am a Registered Nurse and presently completing my Masters of Nursing degree at the University of Ottawa, and as part of my thesis, I am conducting a study with the Community Care Access Centre. The study is [preliminarily] entitled “**Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community**”. The aim of this study is to gain a deeper understanding of the experiences of patients with an ostomy due to cancer during their first year home following surgery. During the interview, I will ask you to describe your adjustment to life with an ostomy, but first, let’s go over the Study Information Sheet and the Consent Form.*

During this time, the principal investigator (PI) will read over the Study Information Sheet with the participant and retrieve consent. Once consent has been retrieved, the PI will continue with the data collection.

Interview Questions

“(name of the participant), I would like to talk to you about your experience with living with an ostomy.” Begin by asking the participant to start at the beginning, explaining how they came to need the surgery and learn of their cancer diagnosis. Proceed to ask the following interview questions in a dialogue/conversation-like manner.

1. Can you tell me what it has been like for you living with an ostomy since you were discharged from hospital?
2. Has there been anything particularly difficult for you?
3. What has helped or hasn’t helped?

Appendix G: Summary of Preliminary Results for Participant Review

Dear participant,

Thank you for your participation in the Masters of Nursing thesis study [preliminarily] entitled “**Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community**”, conducted by Liza L. Padilla, BSc, BScN, MScN-PHCNP(C) student, RN, CGN(C), and her thesis supervisor Dr. Kathryn A. Smith Higuchi, RN, Associate Professor at the University of Ottawa, School of Nursing.

The purpose of the study was to examine the *experience* of patients with an ostomy due to cancer and their care needs within their first three years home following hospital discharge.

Three questions were used to guide the study: Following discharge into the community,

1. What is the experience and care needs of these patients?
2. What are the facilitators to meeting the care needs of these patients?
3. What are the barriers to meeting the care needs of these patients?

Preliminary findings were developed by reviewing participant interviews and finding common subjects within them. Sharing of these findings with participants is part of the normal study process. They are summarized below. Please think about the next two questions when reviewing them:

- Do the subjects describe your experience in transitioning to life with an ostomy after hospital discharge?
- Do you have any comments or questions?

➤ **Everything is Totally Different**

Knowing about changes that have happened to you and your life.

Body Image Changes

Changes to the body and changes in feelings about yourself.

Changes in Activities of Daily Living & Lifestyle

Changes in life’s everyday things and in the way you live your life.

Changes in Being Intimate & the Sexual Experience

Changes in intimacy.

Affording the Ostomy

Problems faced with getting ostomy supplies, and ways of getting them within budget.

➤ **Always on my Mind**

How always being aware of the ostomy and having no control over it forces you to prepare for and avoid uncomfortable or embarrassing things from happening.

Fearing a Situation

Worrying about an uncomfortable or embarrassing situation happening.

Anticipating Problems

Preparing ahead of time or changing activities on purpose to lessen the risk of an uncomfortable or embarrassing situation from happening.

Revealing/Concealing the Secret

The comfort level that goes with letting people know about the ostomy surgery or cancer diagnosis.

➤ **Moving Towards Independence**

Moving towards living your life without help from others.

Healthcare Professional Support

Professional help in the community that helped you get back to living life without help from others.

Learning to Manage Independently

The process of learning how to handle the ostomy appliance on your own without help from others.

Getting on with Life

Accepting the ostomy and cancer diagnosis and carrying on with living your life positively.

➤ **I'm Not Alone**

The help that was there for you after hospital discharge.

Physical Support

Help you received with doing physical tasks.

Emotional Support

Help you received with dealing with your feelings.

Educational Resources

Things that helped you learn about the ostomy and cancer.

Willingness to be Helped

Your willingness to let someone help you or asking for help.

Again, thank you for your participation in this study. If you have any questions or concerns about this research, please contact the principal investigator for this project, Liza L. Padilla by email at [email address], or her Thesis Supervisor, Dr. Kathryn A. Smith Higuchi at [telephone number] or by email at [email address].

Appendix H1: Ethical Approval Notice I – Access to Participants for Data Collection

File Number: H05-10-01

Date (mm/dd/yyyy): 07/22/2010



Université d'Ottawa University of Ottawa
 Service de subventions de recherche et déontologie Research Grants and Ethics Services

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Kathryn	Higuchi	Health Sciences / Nursing	Supervisor
Susan	Brajtman	Health Sciences / Nursing	Co-investigator
Dawn	Stacey	Health Sciences / Nursing	Co-investigator
Liza Lorraine	Padilla	Health Sciences / Nursing	Student Researcher

File Number: H05-10-01

Type of Project: Master's Thesis

Title: Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/22/2010	07/21/2011	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

File Number: H05-10-01

Date (mm/dd/yyyy): 07/22/2010



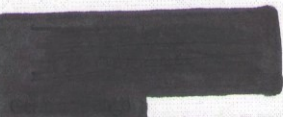
Université d'Ottawa **University of Ottawa**
 Service de subventions de recherche et d'éthologie Research Grants and Ethics Services

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5841 or by e-mail at: ethics@uOttawa.ca.



Protocol Officer for Ethics in Research
 For [Redacted] Chair of the Health Sciences and Sciences REB

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550, rue Cumberland 550 Cumberland Street
 Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
 (613) 562-5841 • Téléc./Fax (613) 562-5338
<http://www.rges.uottawa.ca> <http://www.ssrds.uottawa.ca>

Appendix H2: Ethical Approval Notice II – Approval of Modified Inclusion

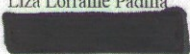
Criteria



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February 03, 2011

Kathryn Higuchi
 School of Nursing
 Faculty of Health Sciences
 University of Ottawa
 451 Smyth Rd
 Ottawa, ON K1H 8M5

Liza Lorraine Padilla


Susan Brajtman
 School of Nursing
 Faculty of Health Sciences
 University of Ottawa
 451 Smyth Rd
 Ottawa, ON K1H 8M5

RE: Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community (H 05-10-01)

Dear Researchers,

The Health Sciences and Science Research Ethics Board has examined your request for ethics approval of the following modifications to your research project:

- ☐ The researchers have changed the inclusion criteria to include:
 - Participants with temporary ostomies due to cancer;
 - Participants who have ostomies that have not yet been determined whether to be temporary or permanent;
 - Participants with permanent ostomies within three years of having had their surgery and discharge from the hospital.
- ☐ If the researchers do not get enough participants they will include participants with ostomies not due to cancer.

Your request has been accepted. The certification of ethical approval delivered on July 22, 2010 and valid until July 21, 2011 covers these modifications.

During the course of the study, any further modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly notify the REB of any adverse events that may occur.

If you have any questions, please do not hesitate to contact me at extension 5387.

Sincerely yours,

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<http://www.uottawa.ca/services/research/rge/index.html>



Université d'Ottawa | University of Ottawa

Service de subvention de recherche et d'éthologie | Research Grants and Ethics Services

[REDACTED]
[REDACTED]
Protocol Officer for Research Ethics
For [REDACTED] Chair of the Health
Sciences and Sciences REB

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<http://www.uottawa.ca/services/research/rge/index.html>

Appendix H3: Ethical Approval Notice III – Renewal for Member Checks

File Number: H05-10-01

Date (mm/dd/yyyy): 08/29/2012



Université d'Ottawa University of Ottawa
 Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Kathryn	Higuchi	Health Sciences / Nursing	Supervisor
Susan	Brajtman	Health Sciences / Nursing	Co-investigator
Dawn	Stacey	Health Sciences / Nursing	Co-investigator
Liza Lorraine	Padilla	Health Sciences / Nursing	Student Researcher

File Number: H05-10-01

Type of Project: Master's Thesis

Title: Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community

Renewal Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/22/2012	07/21/2013	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

N/A

File Number: H05-10-01

Date (mm/dd/yyyy): 08/29/2012



Université d'Ottawa University of Ottawa
 Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:

<http://www.research.uottawa.ca/ethics/forms.html>

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:

<http://www.research.uottawa.ca/ethics/forms.html>

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Protocol Officer for Ethics in Research

For Chair of the Sciences and Health Sciences REB

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550, rue Cumberland 550 Cumberland Street
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 (613) 562-5387 • Téléc./Fax (613) 562-5338
<http://www.research.uottawa.ca/ethics/index.html>
<http://www.recherche.uottawa.ca/deontologie/index.html>

Appendix I: Letter of Support for Site Access



April 14, 2010

Liza L. Padilla, RN, CGN(C), H.BSc, BScN, MScN student
University of Ottawa

Dr. Kathryn A. Smith Higuchi, RN, PhD
Associate Professor
University of Ottawa

Re: Proposal – Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community

Dear Ms Padilla:

Thank you for your invitation to participate in your Masters of Nursing thesis study received April, 2010. Please accept this letter of support and intent to participate from the [redacted] Community Care Access Centre (CCAC) pending ethical approval from the University of Ottawa's Research Ethics Board (REB). At which time, the CCAC will review the proposal and REB approval prior to giving formal consent and initiating participant recruitment.

Yours sincerely,

[redacted signature]
[redacted]
[redacted]
[redacted] CCAC
[redacted]

Community Care Access Centre
Centre d'accès aux soins communautaires



Appendix J: Signed Consent for Site Access

Consent Form for Site Access and Assistance with Participant Recruitment

Transitioning with an Ostomy: The Experience of Patients with Cancer in the Community

Consent for Site Access



University of Ottawa
Faculté des Sciences
Santé
Université d'Ottawa
Faculté de Santé
École de Santé

I have read the letter of information, have had the nature of the study explained to me, and I agree to participate. I also agree not to penalise clients who wish to participate, do not wish to participate, or wish to withdraw from the study.

All of my questions have been answered with satisfaction.

Name of Community Program (Please Print):
Community Care Access Centre (CCAC)

Person Approving Site Access and Assistance with Participant Recruitment:
Name (Please Print): [Redacted]
Title (Please Print): [Redacted] CCAC
Signature: [Redacted]
Date: Sept 08 2010

Person Approving Site Access and Assistance with Participant Recruitment:
Name (Please Print): _____
Title (Please Print): _____
Signature: _____
Date: _____

Person Getting Permission:
Name: (Please Print): Liza Lorraine Padilla
Signature: [Redacted]
Date: September 8th, 2010

There are two copies of this consent form, one copy is for the researcher and one copy is for the study site.