

UNIVERSITY OF CALGARY

Stories of Young Adults with Permanent Ileostomies

by

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A THESIS

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Abstract

The purpose of this study was to reconstruct the individual stories of young adults living with a permanent ileostomy. Using the method of narrative inquiry, seven young adults, ages 24 – 40 years, were asked to share their experiences during one interview session. Narrative inquiry provides for understanding the unique experience and perspective of individuals.

Young adults change physically and cognitively as they progress through adulthood. They face unique challenges including: changing career paths, forming and establishing relationships and changing family and social roles. Having a permanent ileostomy disrupts sequences and paths of adult development impacting quality of life, body image and relationships. These young adults described the challenges of living with an ileostomy as difficult in this phase of their lives. The reconstructed stories allow readers a glimpse into the participants' lives.

Acknowledgements

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Finally, I would like to thank my special friends, Carol Wild and Val Johnson for their support and encouragement.

Dedication

Dedicated to the memories of my husband,

Judge Gerald (Gerry) V. Sinclair

and to

my special friend, mentor and colleague

Fay Moore.

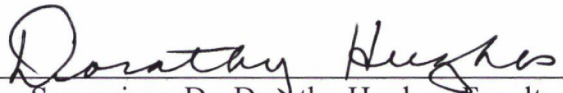
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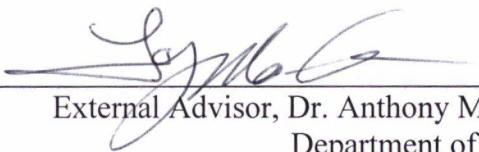
UNIVERSITY OF CALGARY
FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Stories of Young Adults with Permanent Ileostomies" submitted by Lorraine Gail W. Sinclair in partial fulfillment of the requirements for the degree of Master of Nursing.


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CHAPTER ONE

INTRODUCTION

For the past 20 years my nursing practice has been within the specialty of Enterostomal Therapy (ET) nursing. ET nurses provide and manage the care of the patient population who require ostomy, skin and wound, and / or incontinence care. The focus of this study is on one segment of the ET population, young adults living with permanent ileostomies.

Providing nursing care to people who undergo ostomy surgery is complicated and challenging because biological, psychological, social and spiritual needs must be addressed. This is especially true for young adults in their 20's who are entering adulthood and facing challenges of relationships and work and family roles (Bee, 1992). Early adult development encompasses a combination of sequences and paths, internal psychological clocks and external influences (Bee). Adult progression through ages 20 to 40 years differs for individuals, as each person is unique; however, generally during these years changes occur physically and cognitively. Family and sexual roles dominate, work roles change, relationships with friends change, personality grows and changes, and a focus is on major tasks (Bee). A crisis such as ostomy surgery can interrupt a young adult's developing sense of self due to the surgery's effect on body appearance and elimination process. Even when ostomy surgery enhances individuals' physical health, it can be a major life-altering event due to its effect on other aspects of their lives (Beck, 2002).

The terms ostomy and stoma have different meanings; however, they are often used interchangeably when referring to bowel and urinary diversion surgery. Ostomy is a

general term used to refer to surgery creating an opening from the gastrointestinal system to the outside of the body, which serves as an altered exit for intestinal effluent. A urostomy designed for urinary drainage often uses a segment of the gastrointestinal tract to create the altered exit (Broadwell & Jackson, 1982). Stoma is a Greek word meaning 'mouth' and refers to the portion of the gastrointestinal tract sutured to the abdominal skin surface (Broadwell & Jackson). The stoma protrudes through the abdominal wall and is visible (White, 2002). Many technical improvements in the construction of ostomies have taken place since 1756 when the first colostomy was recorded. The basic concept of stoma construction however, remains essentially unchanged (Black, 2000).

Ostomy surgical procedures are performed to treat and manage both benign and malignant disease processes of the bowel. They are often lifesaving procedures and are performed when there is not a medical or surgical alternative (White, 2000). The procedure usually renders individuals incontinent, requiring an external collection appliance (pouch). An alternative may be a procedure in which self-catheterization is performed through a stoma, thus eliminating the need for an external appliance (McGarity, 1992).

Ostomies can be situated anywhere in the digestive system. They are named according to their placement and can be either temporary or permanent. Temporary ostomies often are created in conjunction with other surgical procedures to allow the bowel to heal, including, but not exclusive to: oncology surgery, diverticulitis, ulcerative colitis, Crohn's disease or trauma related injuries (McGarity, 1992). A permanent stoma usually includes a proctectomy involving removal of the anal sphincter mechanism

(Black, 2000) and may be indicated for the treatment of rectal carcinoma, Crohn's disease or intractable incontinence (McGarity).

Ileostomies are created in the ileum, the distal segment of the small intestine. Conditions that may require an ileostomy include: Crohn's disease, ulcerative colitis, familial adenomatous polyposis, necrotizing enterocolitis, aganglionosis, obstruction and chronic constipation (McGarity, 1992). The peak incidence of ulcerative colitis occurs in teenagers and young adults, 15 to 25 years of age, while Crohn's disease peaks in young adults between the ages of 20 and 35 years (Black, 2000; Bryant & Buls, 1992). This places young adults at greater risk for ostomy surgery.

Ileostomies present a particular challenge, as the effluent is usually pasty or fluid and there is a high output compared to a sigmoid or descending colostomy. The difference in the volume and consistency of stoma output dictates different management and appliances. A retrospective study of 1616 patients reported that ileostomies presented with the highest incidence (49 percent) of the study's total complications suggesting an ileostomy presents challenges for patients and the health care provider (Park et al. 1999).

Surgery resulting in an ostomy encompasses all age groups and walks of life. It is estimated that between 42,000 and 65,000 ostomy surgeries are performed yearly in the United States and approximately 750,000 people have an ostomy (White, 2002). At the time of writing I was unable to locate a Canadian National database reporting the numbers of ostomy surgical procedures; however, The ORyX Group in New Jersey compiles ostomy statistical information from Canadian hospitals (The ORyX Group, 2002). In the year 1999 – 2000 this group reported 13,651 ostomy surgeries in Canada,

1,387 of which were performed in Alberta. No separate statistics, on the number or the type of ostomy were available for the young adult age group (20 to 40 years). Today, due to the conception and development of the ileoanal pouch procedure permanent ileostomy surgeries are less common (Black, 2000). Nevertheless a need remains to understand, address, and provide evidence-based care for people living with permanent ileostomies.

Conception of the Study

Over the many years I cared for patients with ostomies I often wondered what it was like for them to live with an ostomy. Reflecting on interactions with patients during clinic visits I sensed that adjustment for young adults was particularly difficult. Life is challenging for young adults as many issues and transitions influence the individual in this developmental period. Unscheduled changes such as acute / chronic illness and major surgery may have major effects on this age group (Bee, 1992). I wondered if there was more to their stories than what I heard during clinic visits, which were largely concentrated on the challenges of physical care. What is it like for them to deal with the altered body appearance and elimination process during this stage of life? I wanted to enhance my understanding of their lives and experiences so I could provide improved patient care and teaching.

Studies over the past years involving patients with ostomies have used structured questionnaires to investigate quality of life, relationship between quality of life and self esteem, relationship between quality of life and body image, impact on working capacity, and sexuality. Other studies have used the same format to compare the quality of life of patients with permanent ileostomies with patients with alternative bowel surgeries. No

known studies have focused on understanding the lives of young adults with permanent ileostomies from a qualitative approach. A better understanding of young adults' experiences living with permanent ileostomies may influence the delivery of care from all health care providers.

Purpose of the Study

The purpose of the study was to understand the experiences of young adults living with permanent ileostomies by reconstructing their individual stories and identifying common or divergent themes across the stories. The human science method of narrative inquiry was chosen to guide this study. Narrative inquiry is a method by which human experience, as it emerges from told stories, becomes meaningful (Polkinghorne, 1988). The goal of the study is to contribute to practice of nursing and the practice of other health care providers who give care to young adults with permanent ileostomies.

Research Questions

The research questions guiding this study were: (a) What are the stories of young adults with permanent ileostomies and, (b) what common and / or divergent themes can be identified across the stories of young adults with permanent ileostomies? These questions were examined using narrative knowing as the theoretical foundation.

Theoretical Foundation: Narrative Knowing

Narrative is a means of giving meaning to experience; it links everyday actions and events into units and provides a framework for understanding past events and

planning future actions. Narrative knowing has a holistic quality and is the fundamental structure of human experience (Connelly & Clandinin, 1990). As human beings and as nurses we live in a world of stories. Story telling is the basic form of human communication; generations have passed on their traditions, beliefs and history in this format. Each one of us by nature live storied lives and we tell stories of our experiences and happenings to one another. The uniqueness of each person's story is what gives it value and meaning (Ornish, 1996). We also learn from story telling what makes us similar, what connects us, and what helps us go beyond the isolation that separates us (Ornish). Listening to an individual's story in his or her own voice is the best means of understanding "...the unique experience and perspective of an individual..." (Atkinson, 1998, p. 5).

Van Manen (1997) describes four fundamental lifeworld themes or existentials that are helpful guides in the research process. These themes "probably pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness" (Van Manen, p. 101). *Lived space* (spatiality) is the felt space of the world or landscape in which we move or find ourselves at home; *lived body* (corporeality) is the recognition that we are always bodily in the world; *lived time* (temporality) is subjective time as opposed to clock time; it is our way of being in the world and placing things in the context of time, and *lived other* (relationality) is the lived relation we maintain with others in the interpersonal space we share with them.

Van Manens's (1997) four existentials are considered to belong to the fundamental structure of human existence. They parallel and help explain the three-dimensional space of narrative knowing: personal and social, place, and temporality.

Clandinin and Connelly (2000) describe four directions guiding inquiries into human experience and fitting into the three-dimensional space: inward and outward, backward and forward. Inward (personal) experience refers to the feelings of internal being, moral dispositions, values, hope, faith and spirituality and outward (social) experience refers to the surroundings or place in the world. The backward and forward direction refers to temporality, the lived time of the past, the present and the future. Narrative knowing positions the researcher simultaneously in these four directions (Clandinin & Connelly).

Narrative brings a unique perspective to qualitative research and pays particular attention to the temporal unfolding of events. Plot is the central structure or organizing themes of the narrative story and how people plot or tell their story partly depends on the meaning their stories have for them (Poirier & Ayres, 1997). The plot weaves the complex of events together to make the story (Polkinghorne, 1988). Narrative understanding knows the entire story in which a series of events occurred.

People struggle to make sense of their often-confusing environment. People are individuals but are also always situated in relationships and social context; therefore, they need to be understood both as unique individuals and in relations. Their narrative story is based on personal needs and feelings and is constantly subject to change as reflection and reconsideration occurs. Inconsistency is part of life and stories are never identical to the lived experience itself; recollections of the actual experiences are transformations of those experiences (Van Manen, 1997). There is life-as-lived, life-as-experienced and life-as-told (Sandelowski, 1991). The narrative is life-as-told and is "...the representation of life rather than life itself" (Sandelowski, p. 163).

Life continually unfolds from birth to death, and the insights of today are the events of tomorrow. Stories are retold and lives are lived in new ways (Connelly & Clandinin, 1990). Each experience had a previous experience as a base and will lead to future experiences. It may be difficult for participants to tell their stories and researchers may find listening equally difficult; but an important task of narrative knowing is "...the retelling of stories that allow for growth and change" (Clandinin & Connelly, 2000, p. 71). Frank's (2000) experience confirms that illness is demoralizing and stories are used "...as part of [people's] remoralization" (p.355). Narrative framework allows a privileged access to human experience for understanding the uniqueness of each person (Frank). Narrative knowing provides the special theoretical foundation for understanding lived experience of young adults with permanent ileostomies.

Significance of Research Findings

Nurses work in an environment of multiple experiences including their own and their patients'; learning occurs when nurses are immersed in these experiences. Nurses can learn to improve their practice by listening to the stories and voices of patients (Koch, 1998). Listening to patients' stories can generate insight into their worlds and mindfulness of their experiences can lead to possibilities of opening conversation with patients in similar situations. Through qualitative research, practicing nurses have the opportunity "...to find meaning in and understand everyday situations with patients, to discuss and communicate their understanding with others, and ... to change their actions or the actions of others in subsequent situations on the basis of that understanding" (Van der Zalm & Bergum, 2000, p. 217).

ET nurses' education focuses on the biological and psychosocial components of caring for patients with ostomies. Understanding the unique personal experiences of patients is also an important aspect of delivery of nursing care. Research data from this study disseminated to peers and colleagues may influence ET nurses' practices by increasing understanding of the challenging life experiences of their patients.

Understanding leads to relevant knowledge, which in turn enlightens practice (Van der Zalm & Bergum, 2000). Understanding everyday life situations and possible future challenges can provide nurses with the practical knowledge to help prepare young adults to adjust living with an ileostomy. The ultimate purpose of this narrative study is to contribute to the practice of ET nursing and to the knowledge base in general of other health care providers. Furthermore, this narrative study gives the opportunity to reflect on direct front-line ET practice and evolve the role into an advanced practice nurse level. Possible questions generated from this study could lead to further research.

Overview of the Thesis

In the following chapter I present an overview of the literature relevant to the study.

Chapter III includes a description of narrative inquiry as method and a detailed report of the research design. Chapter IV offers the reconstructed stories of the participants in the first person using the transcriptions of the interviews. Chapter V offers the analysis of the narrative as I interpreted and found meaning in the data and situated the narrated experiences within the four directions of narrative inquiry defined by Clandinin and Connelly (2000). Common and divergent themes were identified within each direction.

The final chapter explores my reflections on the study and offers implications for nursing practice and suggestions for nurse researchers.

CHAPTER TWO

BACKGROUND TO THE STUDY

A paucity of ileostomy related studies was found in the literature. At the time of writing I was unable to find qualitative publications describing life experiences of people with ileostomies. Quantitative studies were found that measured the quality of life with an ileostomy. Other studies compared life with an ileostomy to life with alternative bowel surgeries.

Impact on Quality of Life

Quality of life is multifactorial and many variables can be used in different combinations to measure the concept. The following variables were used by McLeod et al. (1986) to describe quality of life of individuals with a permanent ileostomy: physical well-being; emotional well-being; lifestyle, including diet, hobbies, sports, travel and clothing selection; work status and overall satisfaction with the ileostomy. Data from 273 questionnaires found that patients with permanent ileostomies reported physical and emotional health as good (79 percent) and excellent (78 percent). A small number (20 percent) felt having an ileostomy restricted their life activities and 3 percent regretted having the surgery. The function of the ileostomy was the one factor that affected their physical, emotional well-being and overall outlook on life.

A similar design found the majority (92 percent) of patients (N – not reported) had become accustomed to their stoma and 79 percent thought they led a normal social

life (Kennedy, 1988). However, 11 percent of the men and 22 percent of the women hated having a stoma even though they reported acceptance of their ileostomy. This was not a comparison study; however, the author (Kennedy) offered the observation that the ileoanal pouch procedure overcomes the psychological problems associated with having a permanent stoma and questioned if formal interviews and postal questionnaires generated correct answers. Awad, El-Gohary, Skilton and Elder (1993) mailed surveys to 113 patients with permanent ileostomies, again using a similar quality of life design with a return rate of 73 percent ($N = 82$). The majority (93 percent) of patients reported they were happy with the stoma and 20 percent reported improvement in lifestyle activities possibly because of a general improvement in health after the surgery.

In another study, using structured questionnaires ($N = 50$) a relationship ($p = 0.0001$) between quality of life and self-esteem was reported (Kelman & Minkler, 1989). The mean scores indicated the overall population had positive perceptions of their ostomy and the management routine (Kelman & Minkler). The sample was a mix of colostomy patients, ileostomy patients and other ostomy patients. It is questionable if a tool measuring quality of life for ostomy patients in general would accurately reflect quality of life for ileostomy patients as people with ileostomies can have very different management concerns.

The quality of life of patients with a permanent ileostomy ($N = 406$) was compared with patients with an ileoanal pouch ($N = 298$) (Pemberton, Phillips, Ready, Zinsmeister & Beahrns, 1989). Overall satisfaction with the results of the operations was similar and the quality of life appeared to be the same. Performance scores, however, indicated the ileoanal pouch group scored higher in seven areas of daily activity equated

to quality of life compared with the group with ileostomies. Although most of the patients with an ileostomy were satisfied, 39 percent desired a change. No matter how well adjusted a patient was with an ileostomy there was a desire not to have a stoma (Pemberton et al.).

Three groups of patients with a permanent ileostomy (N = 406), a Kock pouch (N = 330), or an ileoanal pouch (N = 298) were compared for quality of life (Kohler, Pemberton, Zinsmeister & Kelly, 1991). The presence of a stoma and fecal incontinence impaired the quality of life after a proctocolectomy (permanent ileostomy). An ileoanal pouch, avoiding a stoma offered the best quality of life.

Postoperative levels of satisfaction regarding quality of life and body image were compared between patients with permanent ileostomies (N = 10, mean age 51) and patients with ileoanal pouches (N = 25, mean age 33) (Liddell, Pollett & MacKenzie, 1995). The surgeon had informed the patients of the surgical options and encouraged them to choose the operation they thought would best suit them. There was no significant difference between the two groups on quality of life and body image. The authors attributed this to the encouragement given to patients to choose their surgical procedure.

The aim of an international study (Marquis, Marrel & Jambon, 2003) was to determine if an adapted Quality of Life Index (QLI) was suitable for patients who have stomas. In addition, the investigators used the adapted instrument to collect data on participants' (N = 4,739, mean age 61.6 years) quality of life. The questionnaire was administered six times over a two-year period. The majority of patients had a colostomy (66.5 percent) and 16.4 percent had an ileostomy. The most common pre-existing disease was carcinoma (70 percent). Results showed time was a major factor for improvement in

quality of life. In addition, satisfaction with care received, confidence in self-care and the relationship with ET nurse appeared to impact quality of life.

Three study groups of patients; people with a temporary ostomy as a result of trauma ($N = 18$), people with a temporary ostomy resulting from disease ($N = 16$) and people with a permanent ostomy resulting from disease ($N = 13$) were compared on psychosocial adjustment to living with an ostomy (Pieper, Mikols & Grant, 1996). Four instruments were used to collect data over two years from patients with colostomies ($N = 38$) and with ileostomies ($N = 9$). Results of the study indicated the people in all groups tended to have a high degree of psychosocial adjustment. There was no comparison made between people with a colostomy and those with an ileostomy.

Using the Digestive Disease Quality of Life Questionnaire, Karadag et al. (2003) collected data from patients who lived with colostomies ($N = 31$) and ileostomies ($N = 12$). The authors stated the impact of a stoma on a patient's life is little discussed and is often underestimated. Their findings confirmed having an ostomy profoundly negatively impacted quality of life. They concluded that specialized counseling of these patients by a dedicated health care team including stomatherapy (ET nurses) would significantly improve quality of life.

In summary, the studies in the literature measuring quality of life of patients with permanent ileostomies found they generally adapted well to living with an ileostomy and had a good quality of life. The studies covered a wide time period from 1986 to 2003. One comparison study (Liddell et al. 1995) representing a wide range of age, found no significant difference in quality of life between patients with permanent ileostomies and other surgical procedures. Other comparison studies indicated that surgery avoiding a

permanent ileostomy offered the best quality of life. In contrast, one study concluded that having a stoma profoundly negatively impacted quality of life. There was always a desire not to have a stoma regardless of the degree of adjustment. The question is raised if it is appropriate to use the same quality of life measuring instrument for different surgical procedures and across different age and developmental stages.

Impact on Working Capacity

Fifty-three patients with a permanent ileostomy for a period of six months to twenty-five years were interviewed using a structured questionnaire relating to their life and work situation (Martinsson, Josefsson, & Ek, 1991). The majority of respondents reported their working capacity had not been affected. However, 41 percent reported sick time ranging from occasional days to months in the 2 years preceding the study.

Awad et al. (1993), using a mailed structured questionnaire, found 16 percent of the participants ($N = 82$) with a permanent ileostomy had to change their employment and 34 percent were mildly to severely affected in their housework and gardening. Another study using the same method of data collection reported 11 percent of the respondents ($N = 141$) with a permanent ileostomy moved to another type of work and 23 percent had difficulties with travel (Nugent, Daniels, Stewart, Patankar, & Johnson, 1999). The researchers expressed surprise at the wide distribution of responses: some patients adapted extremely well whereas others found living with a permanent ostomy very disruptive and distressing. The authors suggested that the responses were reflective of the patients' age or pre-surgery condition. The investigators noted deficiencies in the pre-operative counseling and post-operative follow-up and advice.

The studies examining impact of a permanent ileostomy on working capacity found a range of 11 to 37 percent of respondents changed their employment. The studies offered no further information why respondents changed employment. A question emerges from Martinsson et al. (1991) study: the respondents reported no affect on working capacity; however, it would be valuable to know why 41 percent of the sample reported such a range on sick time. The studies did not offer an explanation why having an ileostomy impacts working capacity; further research could explore this question in greater depth.

Body Image and Ostomy Surgery

An early study interviewed 46 people using semi-structured and structured questions to explore body image disturbance by examining sexual attractiveness after ostomy surgery (Gloeckner, 1984). A decrease in feelings of sexual attractiveness (60 percent) accompanied by negative comments was reported during the first year post-operatively. In contrast there was an increase (67.5 percent) in feelings of sexual attractiveness after the first post-operative year up to the time of the interview (mean = 4.6 years). Twenty-five percent of the male respondents (N = not reported) in another early study (Kennedy, 1988) admitted to having some psychological difficulties in sexual relationships. This was particularly apparent in the young unmarried men who had difficulty discussing the ileostomy with their girlfriends.

Several studies using structured questionnaires mailed to patients with permanent ileostomies included sexuality as a variable. In an earlier study (Awad et al. 1993), 74 participants answering questions on sexuality reported a moderate to severe (46 percent)

interference with their sexual life. In a later study of 44 participants, 45 percent reported problems with sexuality (Nugent et al. 1999). In another study (Azizah, Yunos, Choen & Keng, 1998) questionnaires were mailed to patients with permanent ostomies. Thirty-six percent of the respondents (N = 47) reported experiencing problems with sexual relationships. The authors suggested psychiatrists and psychologists might best address sexuality leading to improved rehabilitation for patients with new ostomies (Azizah et al.).

Differences in body image between patients with a permanent ileostomy (N = 4) and those with an ileoanal pouch (N = 3) were examined (Salter, 1992) using a qualitative approach. Data were collected using unstructured interviews. The ileoanal pouch patients were perceived to cope better with their disease, surgery and altered body than patients with a permanent ileostomy. Patients with the ileostomy had negative feelings of body image and expressed difficulties in adjusting to living with a permanent ileostomy.

The findings of these six studies conducted over 15 years confirmed that sexual relationships is one component of quality of life adversely affected by ostomy surgery. Findings suggest strongly that sexuality issues need to be better addressed by ET nurses and other health care providers.

Stoma Complications

A review of 1616 patient data cards compiled by a hospital's Enterostomal Therapy nurses concluded complications from stoma construction are common (Park et al. 1999). Seventy-four percent of the loop ileostomy (temporary) patients and 34 percent of the permanent ileostomy patients had complications. The most common early

and late complication was skin irritation (18 percent) and the investigators concluded that ileostomies, particularly the loop configuration, should be avoided (Park et al.). They also reported 57 percent of participants (N = 273) with permanent ileostomies had problems with peristomal skin integrity. Three groups of patients with a permanent ileostomy (N = 406), a Kock (N = 313), or an ileoanal pouch (N = 298) indicated they had skin problems (Kohler et al. 1991). Thirty-nine percent of the patients with a permanent ileostomy and 36 percent of the patients with Kock pouches reported having peristomal skin problems. The ileoanal pouch patients experienced intermittent daytime perianal irritation. Awad et al. (1993) found in a sample of 113 participants with permanent ileostomies, that 74 percent encountered peristomal skin irritation.

Research literature confirms people with ileostomies, especially the loop configuration have a high rate of both early and late peristomal skin complications. Findings suggest patients require close monitoring and follow-up post discharge to manage and help prevent peristomal skin complications.

Education

Persson and Hellstrom (2002) collected data from nine subjects with ostomies using open-ended interviews to assess their pre and postoperative teaching program. Five subjects had ileostomies, two had colostomies and two had urostomies. Subjects were asked to describe their feelings, attitudes and experiences involving altered body appearance, social and work life, reactions of friends, revealing nature of surgery and expectations for the future. The researchers perceived that participants had received comprehensive preoperative teaching; however, several areas were identified that had not

been well addressed. Some participants expressed severe difficulty in adjusting to living with an ostomy. Participants perceived that health care professionals did not provide all the desired information and emotional support; and expressed the need to talk with someone living with an ostomy. The findings led to a review and modification of the education program and demonstrated the need for ongoing support for patients in the early stages of recovery after ostomy surgery.

Stoma care nurses (SCN) (N = 8) were interviewed and questionnaires (N = 264) were analyzed to understand current practice and preparation for the SCN role regarding patient support, teaching strategies and sexuality counseling (Borwell, 1997). The findings of the multi-method study led to several recommendations: see that a formal support system is in place possibly involving psychologists, evaluate current teaching strategies, revise existing courses and provide a recognized structure for future professional development. It was noted that only one-third of SCNs had recognized counseling training and only 9 percent had psychosexual training.

An Enterostomal Therapy Education Program used a pedagogic strategy to expose ET students to a dramatization of being a person with a stoma (Santos & Sawaia, 2001). Thirty nurses agreed to wear an ostomy appliance containing water for a 24-hour period. Data from the experiences were collected by an open interview. The experience turned theoretic and practical knowledge into something real giving the participants opportunities to examine altered body image, self esteem, identity and sexuality. The study allowed participants to redefine "being a professional", describing changes in future caring, a holistic patient approach and being more cognizant of patients' quality of life.

Shipes (1987) and Elcoat (1988) recognized the deficiencies in the care delivered to ostomy patients and developed guidelines to improve delivery of care. Shipses suggested the important aspects of psychosocial rehabilitation of ostomy patients were not fully addressed by nursing staff due to a lack of time, increased patient loads, and early discharges. Nursing diagnoses addressing the major physical, emotional and interpersonal components of ostomy surgery were developed to improve the physical and psychologic integrity of the patient. Elcoat reviewed the practical information and guidelines for emotional support to help nurses take a systematic, holistic approach towards the physical, psychological and social needs of patients who had ostomy surgery. These guidelines are still reflective of patient needs today.

The literature suggests that there is a deficiency in the psychosocial / sexuality counseling and care delivered to patients with ostomies. Further research examining ET nursing practice and teaching needs of patients would help address and provide comprehensive teaching helping patients' adjustment to living with an ostomy.

Summary

The literature comparing ileostomy surgery with other surgical procedures suggests ostomy patients have varying degrees of difficulty in adjusting post operatively and the operation of choice is the procedure avoiding a permanent ileostomy. Although advancement in surgical techniques has made permanent ileostomies less common, it is still the treatment of choice for patients who do not meet the criteria for alternative medical or surgical treatment. Borwell (1997), Nugent et al. (1999) and Persson and Hellstrom (2002) found deficiencies in pre-operative and post-operative teaching and

follow-up, suggesting health care providers may not be meeting the needs of patients living with an ostomy. This concern needs to be addressed.

No known studies have described the experiences of young adults living with a permanent ileostomy. Unstructured interviews in qualitative research give participants freedom to tell their story. A gap in the literature exists relating stories of young adults with permanent ileostomies. Literature has not singled out young adults living with an ileostomy; studies have been structured on broad groups of patients. Based on past experience I perceived that adjustment for young adults was especially difficult. With a deeper understanding of patients' experiences health care personnel can provide more effective care and support the patient's adjustment to living with an ileostomy.

CHAPTER THREE

RESEARCH DESIGN

The qualitative method of narrative inquiry was chosen to understand the stories of young adults living with permanent ileostomies. Narrative inquiry is a method of gaining a full appreciation of human life and experiences. To come to understand the unique experience of a person, one must listen to his/her voice. Each person's experience is unique and not replicated by any other person.

Narrative Inquiry as Methodology

Connelly and Clandinin (1990) described narrative inquiry as both a phenomenon and a method of study. The story is the phenomena and the narrative is the method of inquiry. Narrative inquiry is founded on the belief that, by nature, people lead storied lives and tell stories of their lives; researchers collect and describe peoples' lived stories and narrate their experiences (Connelly & Clandinin). Basically human experience is storied experience (Connelly & Clandinin, 1992). Narrative is a powerful methodology for understanding the uniqueness and fullness of human lives (Oliver, 1998). The purpose of narrative is to understand how people "...impose order on the flow of experience to make sense of events and actions in their lives" (Reissman, 1993, P.2). It was my intent to listen to the stories of young adults who live with a permanent ileostomy.

Narrative focuses on human experience, has a holistic quality and is a collaborative process (Connelly & Clandinin, 1990). Collaboration indicates a

relationship and the relationship involved in the narrative inquiry process may determine what actually gets told and even how it is told (Atkinson, 1998). It can look at the entire life experience, life as a whole or at significant time periods in a life (Polkinghorne, 1988). Readers may not interpret the story's meaning the same way as the teller intended (Poirier & Ayres, 1997).

The narrative inquiry process involves three areas: the field, field texts and research texts (Connelly & Clandinin, 1992). The field is the place where the inquiry takes place. Researchers arrive in the field, understanding that lives do not begin with their arrival and do not end with their departure. In addition, the understanding of participants' temporal, historical and cultural events is pivotal in making meaning of their lived experience (Clandinin & Connelly, 2000). Researchers in the field need to learn to negotiate relationships, purposes and transitions with the participants (Connelly & Clandinin).

The collected data are referred to as field texts and the researcher creates texts as the experience of the participants is listened to and body language is observed. Interviewing is one widely used method of creating field texts (Clandinin & Connelly, 1994). In the present study field notes and audio taped interviews served as the field texts. Field notes are written records of the interviewer's reflections, doubts and reactions to the interview experience and serve as a reminder of the non-verbal communication that occurs during the interview (Clandinin & Connelly, 2000). The researcher's relationship to the participants' storied experiences may contribute in a positive way to gathering the data. The boundaries between the researcher and the participant expand and contract as the interview progresses. Sometimes the researcher's

personal, private and professional life merges with the specific research experience (Clandinin & Connelly). The interviewer needs to be cognizant that it is the interviewee's story and must avoid leading or influencing the storyteller.

The research texts, the constructed individual stories, are based on the field texts and have distance from the field. The transition from the field texts to the research texts is a time for questioning meaning, social significance and purpose. The questions are who, why, what, how, context and form (Clandinin & Connelly, 2000). The patterns, narrative threads, tensions, and themes within or across the participants' experiences (Clandinin & Connelly) are extracted from the research texts. Researchers need to acknowledge their own presence, understand it and include it in the final research text (Connelly & Clandinin, 1992).

Research Method

The qualitative method of narrative inquiry was used as the basis of this study. This research method was chosen as it captures the holistic experience of individuals and gives value to their stories and experiences (Polkinghorne, 1988). The goal was to uncover meaning in the narrative stories of young adults with permanent ileostomies and to identify common or divergent themes.

Participants

Seven young adults, three men and four women between the ages of 20 to 40 years participated in the study. The age limitation followed the description of young adulthood as beginning around 20 years of age and extending through to 40 years of age

(Whitman, Graham, Gleit & Boyd, 1986). Four participants had ulcerative colitis, two had Crohn's disease and one had chronic constipation caused by autonomic insufficiency. They were fluent in English, and surgically and emotionally stable. The time period of living with a permanent ileostomy ranged from ten weeks to three and a half years. The postoperative time frame from the creation of a permanent ileostomy to interview was limited to less than four years to ensure the participants' stories clearly related to the same lived experience. Longer lengths of time since ileostomy surgery could blur memories of the early post-operative period. In a personal communication a previous patient who has had an ileostomy for over 25 years noted that it is now so much a part of her life it is difficult for her to remember and describe her initial feelings and experiences.

Ethical Approval

The fundamental ethical principles in research include beneficence that seeks to prevent harm and exploitation of study participants (Polit & Hungler, 1999). The research proposal with accompanying letters and consent form were submitted to the Conjoint Health Research Ethics Board and approval for the study was granted (Appendix A). The consent form (Appendix B) gave an overview of the purpose of the study, expected commitment, volunteer nature and confidential issues. Participants were informed that there were no known risks or benefits, nor financial benefits or costs incurred for participation. It was emphasized that participation was strictly voluntary and withdrawal from the study could occur at any desired time. The audiotapes were kept in a secure place by the co-investigator until completion of the study and then were

destroyed. The transcriptions will be kept up to five years in a locked filing cabinet for possible secondary analysis. Confidentiality was assured by changing the names of all the participants and their doctors in the final research report and will be the case in any subsequent publications and presentations.

Recruitment

A colon and rectal surgeon supported my research thesis (Appendix C) and four participants were recruited from his practice in Calgary. The clinic nurse spoke with one participant visiting the clinic who later contacted me. The clinic nurse contacted three other patients, phoning them at home, explaining the study. The contacted patients expressed interest in participating in the study and gave permission for me to contact them. Three participants were recruited by the President of the Calgary Chapter of the United Ostomy Association of Canada and gave permission for me to phone them.

In the initial contact phone conversation, the potential participants received an explanation of the research process and the decision to participate was mutually confirmed. They were informed that the interview would last approximately an hour during which time they would be asked to tell their story of living with a permanent ileostomy. It was explained the interview would be informal and unstructured. Atkinson (1998) stated that unstructured interviews are most effective in achieving the goal of obtaining the person's story in the manner that the individual wishes to tell it. The date, time and location of the interview were established.

Data Collection

Data were collected in one in-depth interview at a convenient time and place for the participant. Data collection from the seven participants took place over a six-week period. The letter of introduction (Appendix D), which briefly explained the study and informed consent (Appendix B) were reviewed with each participant prior to signing the consent form. The participant kept the letter and a copy of the consent. We conversed for approximately ten minutes prior to turning on the tape recorder and beginning the interview. I knew three participants from my previous ET nursing practice and the conversation prior to taping served as a vehicle for renewing our relationship. For the four participants I was meeting the first time this conversation helped to establish a comfortable relationship. I took field notes of my reflective thoughts and observations during this conversation, during the taping and following the interview. I informed participants the tape recorder could be turned off at any time they so wished.

I encouraged the participants to begin their story at any point in their lives where they wished. Six participants chose to start the interview beginning with their disease process. I had some guiding questions to assist with the flow of the interview; however, I found it was unnecessary to use the questions as the information was already woven through the participants' stories. The length of each interview ranged from one hour to two and a half hours. The participant and the conversation flow controlled the time. Following the first interview I transcribed the audiotape and discovered that the placement of the tape recorder was crucial in recording all the conversation.

Data Analysis

I transcribed three of the interviews and a hired transcriptionist completed four interviews, which I later reviewed with the audiotapes for accuracy. Narrative inquiry involves *narrative analysis* and *analysis of the narrative*. The purpose of narrative analysis is to configure the description of events into a story. The narrative analysis provides the framework (story) in which data cohere in an interesting way (Polkinghorne, 1995). The word “story” suggests misrepresentation or untruthfulness, but in narrative knowing story refers to the narrative (spoken or written) describing life events (Polkinghorne). Using the transcripts of the interviews I constructed each participant’s story in his or her own words.

Analysis of the narratives works across the stories locating and describing common themes between the stories. I made notations in the margins of each story identifying thoughts, emotions and events uncovering common themes. The stories were also examined for existing divergent themes. I returned to the texts of the interviews and field notes for reflection numerous times to ensure the final research texts are accurate accounts of the participants’ stories.

Qualitative Rigor

There is no formal and consistent procedure for determining narrative validity and this continues to be discussed (Clandinin & Connelly, 2000). Researchers are cautioned not to squeeze the language of narrative inquiry into a language created for other forms of research (Connelly & Clandinin, 1990). Narrative truth is separated from other kinds of formal science by emphasizing the life-like plausible story (Sandelowski, 1991). The

concept of trustworthiness establishes rigor in qualitative research; the goal of rigor is to accurately represent participants' experiences and "...is often determined by the study participants" (Streubert & Carpenter, 1999, p. 17).

Two terms describing operational techniques to demonstrate trustworthiness are credibility and transferability (Streubert & Carpenter, 1999). The researcher, in reporting the perspective of the participant, becomes the guardian and defender of the participants' truth (Van Manen, 1997). The underlying standard in narrative inquiry is that the storytellers have the final say; they are the ones to determine what gets told, how it fits together, if it is a valid story and whether it stays the same or gets changed (Atkinson, 1998).

Member checking is a method of validating the credibility of the data by verifying with participants the accuracy of the research text as true to their experiences (Streubert & Carpenter, 1999). Four of the seven participants were given their own story for verification of its accuracy. The four participants discussed the content of their story with me during a meeting, or by telephone. Each participant confirmed that the story constructed was an accurate representation of his or her experience. Two participants requested a copy of the final research report, which I will forward to them at a later date.

Credibility also refers to the researcher. The researcher's education, qualifications and experience should have a connection to the research topic (Polit & Hungler, 1999). I am an enterostomal therapy nurse with 20 years of extensive related experience and I am confident the criteria of trustworthiness and credibility were addressed in this study.

Transferability refers to the probability that study findings fit into similar circumstances outside the study and are viewed as meaningful and applicable to its audiences own experiences (Streubert & Carpenter, 1999). The researcher has the responsibility to provide sufficient descriptive data so readers can evaluate the applicability to other contexts (Polit & Hungler, 1999). By providing extensive and detailed descriptions of the participants' experiences and reflecting on my past ET nursing practice I suggest that the findings of this study have potential transferability.

In the next chapter I present the stories of the young adults in their own words. Their stories offer insight into their world of living with disease and a permanent ileostomy. Readers are invited to form their own interpretation of the participants' stories.

CHAPTER FOUR

LISTENING

Listening is listening. Listening well means caring for,
respecting and honoring the other person's life and
story.

Robert Atkinson, *The Life Story Interview*

In this chapter I present the lived experience of a significant piece of the participants' lives. This significant time revolved around the struggle with their bowel disease and ultimately receiving a permanent ileostomy. The emplotted stories were constructed using the transcriptions of the interviews. The resulting stories, written in the person's own voice constituted the narrative analysis (Polkinghorne, 1995). Using a person's own voice and words is the best method to explore the unique experience and perspective of an individual (Atkinson, 1998). This chapter addresses the first research question: What are the stories of young adults with permanent ileostomies?

Narrative is life-as-told and every human experience is unique and not replicable by another person (Polkinghorne, 1998). People's stories are fundamentally the interpretations of their self-understanding of their own experiences (Atkinson, 1998). The following stories are personal and unique. In constructing the stories I remained as true as possible to each participant's words. Editing was done to delete repetition and extraneous information. In some areas I found it necessary to change the sentence structure, add or delete words and change the order of the narrative. This was done to make the story coherent, flowing and interesting for the reader. I found it challenging to determine what components to safely eliminate without detracting from the evolving

story. The stories represent experiences as understood to be significant to the participants. Readers can gain understanding by reading the stories and forming their own thoughts on the meaning of the participants' stories.

As the subjects shared their stories, occasionally strong and painful emotions surfaced. At these points I offered to stop the tape but those offers were declined. Usually the emotional reactions were short-lived, however pain and tears were evident throughout most of the interview for one subject: despite this she insisted upon continuing. I personally experienced anger upon learning that some people had been subjected to occasional indignities and to the absence of compassion and empathy.

Each story is prefixed with a brief description of the participant. I found it helpful to speak with each participant and take field notes prior to beginning the tape. The conversations were generally about their diagnosis, surgeries and families, giving us the opportunity to become somewhat at ease with each other. I invited participants to begin their stories at a place of their choosing and progress through their stories in their own direction. Some of the participants moved through their stories in a fairly chronological order, others did not. On occasion the content of their conversation generated a question from me but the stories were told with minimal intrusion.

Anne's Story

Anne is an attractive young lady, 38 years of age, single and works full time for a mortgage firm. The interview was held in her townhouse, which she is busy renovating and redecorating. At age 21 Anne was diagnosed with Crohn's disease and is the first

member of her family to be diagnosed with inflammatory bowel disease. She chose to begin her story with her first operation.

I had surgery in November 1998 and I remember waking up in the operating room and looking to see if my abdomen was still open. I asked the nurse if I had an ileostomy. She tried to be gentle when she said, “Yes” but I remember screaming and screaming at the top of my lungs. They gave me something for pain as fast as they could and when the drugs started to work I finally calmed down. The next day I remember Dr. A. coming in, sitting on my bed and apologizing. He explained that he had to do a subtotal colectomy and a temporary ileostomy. I made up my mind I was going to be okay, the ileostomy would be closed and I would return to being *normal*.

At about four days post-operatively I started to cry and could not stop. I stayed only six days in the hospital, which was good. I remember when the ET nurse started teaching me how to change it, I was crying, my hands were not coordinated and I was sure I would never manage my own care. The nurse kept her hand on my shoulder and seemed to understand how difficult it was for me. Now I can do it in three minutes flat without even looking, so she was right.

I was 21 when I was diagnosed with Crohn’s disease. I had periods of diarrhea, cramping, bloating and gas, severe fatigue and abdominal pain. At this time I worked as a unit aide on a medical unit of a large hospital where people with Crohn’s disease and people with ostomies were admitted. I had seen the worst of the worst. When Dr. G. told me I had Crohn’s disease I totally freaked out and became hysterical. Over the next 12 years I continued to have episodes. I took Asacol[®], which gave me no relief and prednisone, which gave me some relief of the symptoms. Prednisone was stopped after

muscle-skeletal complications occurred in my hips. Tylenol #3[®] relieved the pain. In July 1998 my mother insisted upon taking me to the emergency, I was sick most of the time and had lost 25 pounds. On admission to emergency my hemoglobin was 46, I was diagnosed with hemolytic anemia and immediately transfused. I received blood every two weeks for a total of 18 units.

In October 1999 nearly a year after the surgery [temporary ileostomy] I was booked for closure. I had a *gut* feeling before the surgery that the stoma was not going to be closed. Multiple abscesses were found in my abdomen and pelvis and the surgery proved to be complicated. Strange thing, before I had the ileostomy I never had an abscess. The abscesses always occur around the stoma. Psychologically that makes me hate the ileostomy more; I can see Crohn's on the stoma. There is something good about not being able to see the Crohn's ulcers. Now when I feel sick, I take off the bag and think oh look I'm sick, the Crohn's is visible.

I have a true hate relationship with the stoma and I call it "Egore" but I have not let it ruin my life. I think I lead a normal life. I have a house, a good job, am involved with a small musical theatre and volunteer work. I do not think people understand why I am so angry, bitter and hate it so much. I lost a large piece of me, part of the ileum and the entire colon. I have an ugly horrible apparatus sticking to the front of me and I am still sick. It is so ugly and it is not a trade off. I am not giving up body appearance and image and gaining improved health. Maybe if I were healthy I would not hate it so much. I take Remicade[®] about every eight to ten weeks to treat the reoccurring abscesses. Every time I have a treatment I wonder if this is the time when the Remicade[®] is going to

stop working. I also wonder when it ceases to control my Crohn's disease and abscesses will there be another drug on the market that will work for me?

I am still single and I am unsure if the ileostomy or disease plays a part. I met Bill when I was very ill in August of 1998 and he has been a wonderful friend for five years. He became interested in me because of his belief and interest in herbal medicine and natural health alternatives. He thought I was anemic and pregnant because my belly was so distended. He is one of the few people who have gone through this surgery with me. The first time I broke down and cried he was with me. I was still in the hospital, and we were visiting sitting by the chapel. I started to cry and we talked until one o'clock in the morning. We are really good friends and he knows how much I hate it. He asked to see my stoma so he would have a better understanding. We are intimate in one sense, but we are not. We are very open and honest with each other. He does not think it is a big deal. His attitude is, "How many square inches of your body? The rest of you is gorgeous and you are a beautiful person." My attitude is, "You live with it and then tell me how you feel!" It is easy when it is on someone else and you do not have it all the time.

We have never been free to date each other due to one or the other being involved in a relationship. Maybe we are just meant to be really good friends forever. You meet a lot of people in your life but there are not a lot of people you trust with your life and Bill is one person I would definitely trust with my life. I have dated other men, one for almost three years. He was absolutely amazing before my last surgery when I developed the draining abscesses. He helped me change the dressings while I was at home and he

was with me everyday at the hospital. In a crisis situation, he was great but it took me three years to see him for what he really was.

For the first two to three years after I had the ileostomy I had what I call *blowing a gasket*. They occurred in the middle of the night and at work. I had just started a new job when I experienced one and I had to ask my boss if I could run home for a short time. I had to change everything. My boss said, "Sure, go, don't worry about it." I had not told my boss I had an ileostomy but after this major leakage occurred I felt I had to tell him. I told him the next day but he already knew. I do not know who told him; I think it might have been Bill. It was not easy to tell my boss; I was very nervous. It was a nice summer day and I asked him to come for a walk. I did not want all the staff to hear our conversation. That was my biggest concern but I felt I could trust him not to tell anyone. I started by explaining Crohn's disease and he said he knew about Crohn's disease. He kept quiet for a short time while I talked but finally he told me he knew I had Crohn's disease and an ileostomy. It did not matter to him what I had, so long as I was efficient performing my job. He also liked my sense of humor and we became good friends.

I am always scared during a job interview that if I tell that I have Crohn's and an ileostomy I will not get the job. All other things being equal, if I am stacked up against someone who does not have a chronic disease, they are going to get the job. Telling a woman is different than telling a man. Women respond emotionally and men respond intellectually. One female boss started crying when I told her about my surgery. Another time I had a supervisor whose daughter had a temporary ileostomy, which was wonderful for me because she understood. There are people I will never tell because I do not trust them, and I do not feel safe with them. It is a gut feeling, which is pretty funny, because I

do not have a lot of gut left. But I am not the person who really tries to hide it either.

I have been through enough in my life if people cannot deal with what I have gone through, it is not my problem. I need to trust people and I need people to accept me for who I am.

Going through surgery and having an ileostomy changed me. I would rather have not woken up. I used to be the forever optimist. Now I am the opposite - if something can go wrong, it will. I am living proof. I prepare for the worst, hope and dream for the best and settle for anything in between. I was never going to have surgery. I would have died before I had surgery and an ileostomy. If Dr. A. had given me different odds than a one percent chance of a permanent ileostomy and a five percent chance of a temporary ileostomy, I would never have signed the consent. They would have had to drag me to surgery kicking and screaming, or I would have had to be unconscious and my parents sign the consent. One good thing has come out of this - I will fight twice as hard to get something to work. I do not take no for an answer. The best thing that came out of this was my friend Yvonne. She died in April. We met in the hospital, were instant friends and became very close. I miss her.

The ileostomy has totally changed my life. Not necessarily in a bad way for my career path but now I feel my career is all I will have. I will never get married and I will never have children. I used to be a model. I modeled for two years but I will not model again. I think I am smarter than the average person, I have a lot of talents and I am just as good as anybody else but I am damaged goods. I am involved in musical theatre but modeling and acting are different. In modeling the focus is 100 percent on you. When you are acting and singing, the focus is either on your voice or the character you are

portraying. I can lose myself in acting and in the production I portrayed the character Suzanne. For three weeks I was completely and totally that character.

My Mom has a different attitude towards my ileostomy since she had surgery and came home with a catheter in her bladder and wearing a pouch. She is more sensitive and now understands why I hate the ileostomy. She realizes that it is not fun, is a lot of work, is expensive and is ugly. I think she struggled with me having the ileostomy but she was thankful I was alive. My dad has always been my rock. We do not talk much, but he gives me great hugs. I can see it in his eyes he too wishes I did not have this thing but, more so, he wishes I was not sick.

The care of the ileostomy is not too bad once you get past the emotions of hating it. But if I don't have to deal with it, I don't. I am allergic to the flanges. The first 24 hours after I change it, my skin is itchy and sore. I take Reactine[®] about an hour before I change it then I can sleep through the night. When I first had it I was still skinny and I could hide it a lot better. Then I gained 20 pounds, which is unusual for a Crohn's patient to gain weight. I had to buy all these new clothes and find it very annoying to spend money on clothes that I do not necessarily want to buy. Also it is easier for people to figure out I have an ileostomy. I empty the pouch about every hour to two hours. As soon as there is a small amount of drainage in the pouch, I feel compelled to empty it.

I talk with people who are in similar circumstances and I think this involvement is important because there is nothing better than talking with someone who has been there and done that. No one can understand the experience the same as someone who has lived it. If people ask me what it is like to have an ileostomy, I am not going to lie and tell them it is the best thing in the world. But if you are sick and an ileostomy is going to

cure your disease, then it is a good thing. The amount of information I offer a person depends upon how much they ask. Also everyone needs to do their own research and know their own body. If you do not understand your disease and body, how can you make informed decisions?

I remember three or four nurses who stand out when I had my first surgery. I particularly remember one night when a nurse was helping me drain my bag. I broke down and could not stop crying. She sat with me for about an hour and we talked and talked. There were four nurses who managed to convince me that, with time, I could deal with the ileostomy and be fine. Emotionally I hate it but I think I cope mentally. I keep very busy and then I do not have time to think about it.

Traveling was a bit of an interesting experience. I flew from the Okanagan to home one time and had to explain what my supplies were and why it was necessary for me to carry them on board. They did finally let me board. In the past when my Crohn's disease was the least bit active I was not comfortable staying with friends. I preferred staying in a hotel. Now with both an ileostomy and Crohn's disease, I still prefer staying in a hotel. I am very uncomfortable in someone else's home.

I know I do not have a choice but I hate the ileostomy. However, I will not slit my wrists. I wonder sometimes if I had been better prepared for the ileostomy would things been different for me? I may be getting a good promotion at work and I have to finish these house renovations. I have a sense of humor about everything and I have never stopped laughing.

Bob's Story

Bob lives out of town so the interview was arranged to coincide with his surgeon's appointment. Bob is 33 years of age, single and lives at home with his parents. He is employed part time and is a part time student. Since 1996 he has had 18 surgical procedures and has trouble remembering all of them. Bob was diagnosed with colitis in 1996; he is the first member of his family to be diagnosed with inflammatory bowel disease.

In January of this year [2003] the ileoanal pouch was removed and a permanent ileostomy was made. Within a week of being discharged from hospital I knew it was the right thing for me. There will be no more trips to the hospital. Since 1995 I have probably been in the hospital 18 to 20 times. When I had the first surgery, the ileoanal pouch, in the summer of 1996, I do not remember if I was told about the temporary ileostomy. We all assumed the ileoanal pouch was going to work but I started developing fistulas and they kept reoccurring. I had three reversals and each time the ileostomy was closed I thought okay this time it is going to work. After zero percent success, something had to give. Last year I was given the options of a permanent ileostomy or continuing with reversals for the remainder of my life. Enough was enough. I made the decision.

I live at home because of my illness and my parents help me. There were times I had so much pain I could not walk up the stairs and Dad carried me. I manage my own ileostomy care; I do not want my mother helping me. In the beginning the physical care of the ostomy scared me. I was used to going to the bathroom using the bottom end and then, all of a sudden, I have this small piece of colon sticking out of my stomach wall. It

was the shock of my life one day when I was changing the pouch and started having a bowel movement. I hopped in and out of the shower trying to put on a new pouch before anything else happened. I have to check the pouch every so often to see when I need to go the bathroom to empty it. It is no problem for me now as I am used to it. In the beginning it was an imposition but I have had an ileostomy on and off since 1996. Each time I had another temporary ileostomy, it became easier and easier for me to live with it.

Timing is everything in managing the care and I still have the odd accident. It all depends if I eat late at night and how much I drink. The body hair around the stoma is a problem; I should shave more often than I do. Sometimes the skin gets very red and that is my fault; I am lazy and do not change the pouch as often as necessary. If I have a small leak, it does not bother me; I tape on a gauze pad and wear the pouch for another day rather than changing and I know this is why I have red skin. I often change in a hurry and do not take care with pouch removal, causing the skin to get even worse.

At times I wish I did not have an ileostomy. But for me it is the issue of control. Now I control when I go to the bathroom. Before, it was always urgent when I needed the bathroom and sometimes I did not make it. Instead of having accidents in bed, at work or while driving, I now have control. I have had a few accidents with the ileostomy pouch because I let the bag get too full and it explodes, but I can live with that. Before I leave home or work I feel the pouch and know I can make it to where I am going. I no longer have to stop en route and use a bathroom like I did before I had the ileostomy. For me, control is the best part of living with an ileostomy.

In 1996 or 1997 Dr. A. recommended I stop drinking and I quit for four and a half years. But I slipped. You only live once and now I go to the pubs and bars and have

a couple of drinks but I no longer get drunk. I did that a couple of times and I had a couple of major pouch leaks. Fortunately I was at home when they happened.

All my co-workers know I have an ileostomy. At first it was hard telling people but I do it in a joking manner and now nearly everybody knows. It is better to be open about everything rather than trying to hide it. I did have a girlfriend and she was fine with it but we broke up. I started seeing someone else but one time I had a small accident and that freaked her out. It was my fault; I did not change the bag when it was necessary. It was, and still is, difficult to discuss the ileostomy with girls. The intimate issue is probably the worst part of having an ileostomy. It is not difficult with my co-workers who are males because it is a guy thing. I am told once I find the right person, she will understand.

I have to wear baggy clothes because my output is so high and I wear the bag outside of my clothes. I wear jeans only in the wintertime when I wear a baggy sweater to hide the pouch. If I have my pouch inside my jeans I get a big bulge and it does not look right. I have to wear a lot of sweat pants but that is fine.

I still have not figured out what helps absorb gas and slow bowel movement. I have been trying a little bit of everything and I still have not found the answer. I take Tylenol #3[®] for the codeine and that slows down the bowel. I do not take them every day, only when the output is high. I drink Pepsi[®] with no problem, but one time I drank something different and I had a major problem. It depends too on what you eat as well as what you drink.

I have quit school twice, the last time in November of 2002. My stoma prolapsed about four inches and I was in severe pain. My roommate drove me to the hospital and I

had emergency surgery the same night. Apparently my bowel was gangrenous. I fell behind so much at school I had to drop out. The program I am taking has two tracks and I plan on changing to the longer program and hope to complete it. The ileostomy affects my ability to do the necessary heavy physical work at my job. My boss knows my condition and he told me not to do the heavier work and my co-workers do not mind because they know my condition. Now I have another stomach hernia and I do not know if it can be repaired. The wall of my abdomen is very weak because of numerous operations I have had. I wear a support belt and it helps control the hernia a bit but it is getting worse.

I had excellent care in all the hospitals. I am always scared to ask the nurses questions but maybe if they had taken the time to ask me if I had any questions or concerns I would have been able to tell them or ask. After my first operation in 1996, a friend of my Dad who has an ostomy talked with me and he gave me some *do's and don'ts*. You learn from other people. My first operation was emergent and there was not enough time for information to be given to me. The written information I received after the operation was very helpful. I eventually discarded it because I do not need it anymore and I remember the contents. Make a statement in your thesis that it helps and makes it easier to adjust to living with an ostomy if you can talk with someone who has an ostomy. The ET nurse tried to find me a visitor but he never came. There is a support group where I live and I want to help with their visiting program, however I was sick last winter and could not help. I will phone them again now I am feeling better.

There are days when I do not want an ileostomy but there is nothing I can do about it. It is part of my life and I just have to deal with it and go on with the rest of my

life. The only advice I have for other people who may be having an ileostomy is, "Don't let it bother you, it's part of life and if I did not have one I would be six feet under ground. Take your pick which one you want."

Carol's Story

Carol is 40 years of age, married for 22 years and has two teenage sons. She was diagnosed with ulcerative colitis in 1984. Carol is a petite pretty lady dressed casually in slacks and a blouse. Her home, spotless and tastefully decorated, is in a new suburb of a large city. She invited me to sit at the kitchen table overlooking a deck and the backyard. After I had been seated a few minutes, her youngest son came into the kitchen for a snack and Carol introduced us. I had the clear impression he was checking on me and making sure his Mother was all right. Carol works part time in a retail store and her husband works out of town. Carol has 16 siblings and no known family history of ulcerative colitis or Crohn's disease. Carol chose to start her interview with her past history.

I was diagnosed with colitis in 1984 and about ten years later I had surgery. I had a J pouch made with the good part of my large intestine. That was a downfall. I would not advise anyone to have that surgery. I did not know it was not guaranteed and wish I had known more at the time. The temporary ileostomy was reversed in three and a half months and from that day I always wore a pad because of constant drainage from the rectum. For ten years I had pain and continual rectal drainage. I took a lot of pills and finally, last year in July, I decided to have a permanent ileostomy. After surgery I remembered a lot about the stoma care from the temporary ileostomy ten years ago. But there still is a lot of adjustment.

When I had the J pouch about ten years ago I did not know things could go wrong with the operation. I had constant rectal leakage and wore a pad all the time. When I menstruated, I went through hell. I took about 30 pills a day and I really did not know what I was doing. At this time my husband was a fisherman and was gone for ten-day stretches. When he came home, he would find me in the corner crying. Whenever I took a shower I screamed with pain and was physically exhausted. I changed pads frequently and my skin in the rectal area was always raw and painful. Sometimes I left work, went home and sat in the bathtub. My Mother had an old recipe she used for bad diaper rash on all her babies. My sister made the recipe for me and it gave me some relief from the pain.

My husband thought a permanent ileostomy was my only option. I started smelling myself from the rectal leakage and I was frightened. For twelve months, I cried, talked to myself, prayed and phoned my dad's preacher. Finally I decided to have a permanent ileostomy. I probably should have had the surgery five years ago but an ileostomy was the last thing I wanted.

The surgery and recovery were difficult for me and I was in hospital for 16 days. I got an infection and was afraid I was going to die. It was a bad experience for me. I suffered and had a lot of pain. Looking back, I do not think I could go through surgery again. But I am a fighter and had the strength and will power to have the surgery, get better and get on with my life with my family. My husband gives me a lot of support.

Most of the nurses were awesome but some nurses did not listen to me. I knew I was not ready to be up by myself to wash. I tried managing by myself but I was really sick and almost fainted. I needed help and after that episode my husband always helped

me wash in the morning. The stoma nurses helped me with the ileostomy but the other nurses did not help or teach me about the ileostomy. The stoma nurses gave me a couple of information sheets but I think there should have been more information given. After I returned home the ET nurse here helped me with my care and gave me lots of information that I keep in a binder. My husband was at home and also helped me with my care. The ileostomy does not bother my husband but sometimes it bothers me. I learned to deal with it, with time it becomes easier, another routine, like brushing your teeth. There are many more supplies available to help with the stoma care compared to ten years ago.

Clothes are an issue for me with the ileostomy and I cannot wear everything I would like. However before I had the ileostomy clothes were an issue too because of the drainage and the pads I wore. Today, special clothes are made for people who have ostomies. They even make bathing suits. I have not been in the water for 19 years because of the rectal drainage. I wore a pair of shorts last week for the first time in years and someone said I looked nice. Wow! I am going to try buying a bathing suit. You can always work around things to make your life wonderful and once the clothes issue is solved, I will be just fine. I noticed the circle of the wafer can be seen through my clothes. If anyone looks at my abdomen and says anything I will tell them to mind their own business. Accept me like I am.

My first day back at work was terrifying. I felt my ileostomy pouch was falling off and when people looked at me I was frightened. Working exhausts me but I cannot leave my work for someone else to finish. Some people know about the ileostomy and some people do not. I was afraid to lift anything at work because I was very concerned I

might damage the stoma and require more surgery. More surgery scares me. My stoma went in [retracted] one night at work and the pouch leaked. I was very angry and cried because ten years ago when I had the temporary ileostomy my pouch never leaked. Then I had to tell my boss about my surgery because I needed to go home to change everything and he said it was okay for me to leave. When I got home I had to figure out what I was going to do with the retracted stoma; so I started pushing like this [demonstrating on abdomen] and it popped out. My skin around the stoma was very badly burned from the leakage. I had three more leakages and I said, "This can't happen, I cannot have pouch leakages." I was very angry because I went through major surgery to be rid of rectal leakage and now the ileostomy pouch leaks! The stoma has gone flat [retracted] twice more. Generally I have a beautiful stoma but I like it out and I panic if it is flat. Sometimes I touch him just to see if he is out and when it is out I know I am okay.

The ileostomy was positive for sex. Sex life is a lot better and the ileostomy does not get in the way. My husband and I have been together for 22 years. We have ups and downs but always work it out. If anything happened to us tomorrow, it would not be because of my ileostomy. I told him I could get special pouches for intimacy and he said, "I don't need it. You are healthy now and that is the main thing in life."

I was a bit nervous at first looking after my stoma but I became used to it. I do not change the pouch every day but I still have to look after it. Sometimes the stoma bleeds when I clean it but I do not panic as much now as I did in the beginning. I am afraid to take a bath or a shower with my pouch off in case the stoma starts working. My skin itches a lot and I wish the flanges did not sit so high on my body. I am going to look at the children's sizes to see if they fit better. The reality is I am a better person, I feel

better, try not to worry and take one day at a time. But I still need time to adjust and that is up to me.

My oldest son blames himself for my illness and ileostomy because I was diagnosed with colitis after he was born. He is not at fault and I try hard to make him believe that my pregnancy with him did not cause the colitis. My youngest son is nervous about my ileostomy but I explained that I am healthier now and no longer need to take drugs. My sons have not told any of their friends about my ileostomy.

The best part of having the ileostomy is that I am living again. I was sick for 18 years of my life. Often I could not walk, never went camping or rode my bike and always had to be near a washroom. I could not shower or bathe without being concerned about the rectal drainage. Now I have to make only minor adjustments. I want to try to do everything and whatever I could not do for the past 18 years I am going to do now.

Doug's Story

Doug is 24 years old, single and graduated from University this spring (2003). He is unsure if he wants to find employment using his degree or pursue further education. He has temporary work for the summer and lives at home with his parents. He was diagnosed with ulcerative colitis in his first year of university. He chose to have the interview in my home.

It started when I was away in my first year of university [fall of 1997] and I came back to Calgary to visit some friends. Just suddenly one night I was not feeling well (diarrhea), so I stayed home for a couple of days before returning to school. But I continued to have diarrhea with blood. I did not think too much about it, just thought I

had food poisoning. I finally decided to go to a doctor and he thought the same thing, food poisoning or maybe a parasite. He told me to return to Calgary until I felt better. I did not improve and visited our family physician. The first question I was asked, "Is there a family history of Crohn's or colitis?" There is no history of either in our family, so that was brushed aside. I was given antibiotics and returned to school. Two weeks later, I still was not any better and stool samples were taken. My parents started to worry because I had now been fairly sick for about four weeks. They called a friend who is a physician and he arranged for an appointment with Dr. G.

I had a sigmoidoscopy and although the results were conflicting, Dr. G. thought I had colitis. He prescribed Salofalk® but three weeks later I was still losing weight, felt terrible and could not eat. Next he prescribed prednisone and said it was guaranteed to work, that it worked for everybody. I got progressively sicker and sicker but I made it until after Christmas and then my mother called Dr. G. He admitted me to hospital and I had TPN, many x-rays, prednisone and other drugs, and as a precautionary measure Dr. G. asked a surgeon to see me. On the morning of my fifth day in hospital following more X-rays, the surgeon visited me. He said he had good news and bad news. The bad news was I would not play football that year, I would miss a year of school, I required surgery and a temporary ileostomy. But the good news was I would be cured. My mom was with me and we were shocked. I figured I would return to school in a couple of weeks and play football. Playing college football was my dream and really exciting for me. And now this! I was not well enough to have the required surgery in one stage, so the procedure required three separate stages. The anesthetist told me I needed blood and I

would probably be in ICU after surgery, which made me think this was fairly serious and I started to get scared. Actually I was terrified. I went for surgery about two hours later.

When I woke up I had severe pain but I was on a unit, not in ICU. The first clear memory was the next morning when the nurses made me get out of bed, sit on a chair in the bathroom and wash. I looked at my abdomen that was still covered in the surgical scrub coloring and saw numerous staples, a huge scar and a bag hanging. It looked awful and I was upset. I guess at that age you are a little vain. I worked out and prior to getting sick I was in good shape. It hit me what actually happened and how serious it was but I knew I was tough and eventually would be okay but it really hit me hard.

I told my parents I did not want my friends visiting but they disagreed. My best friend came the first afternoon and although it was tough, overall it was better for me. My friend and I talked and I realized although I had all this stuff happen, our friendship was the same. I am glad my parents disagreed with me because seeing my friends helped. I told my closer friends what surgery I had and they told each other, which was fine with me. The more they visited, the more I thought maybe my life would not be affected as much as I originally thought.

I thought I was learning to deal with it pretty well. Then I went home and began to realize how different things were but I felt fairly comfortable at home. I remember the first time I went out with my friends; we went to a movie and I do not remember seeing it. Through the entire movie I worried and frequently went to the bathroom to check the pouch - was it getting too full, was it going to leak and I imagined everything happening. Maybe I was not dealing with the ileostomy as well as I initially thought. I went out with

my friends again the next weekend and it was the same scenario. I watched the basketball game in total fear that the pouch would leak. I went to the bathroom every hour to empty and check the pouch. I just wanted to go home.

I did not really get back to my normal life. I kept thinking I would wait until the ileostomy was closed, the surgeries finished and then I will be normal again. I went out with my friends but I did not play football and never dated. It was a pretty tough time for me. Looking back I think the sooner you start doing your normal activities, the sooner you learn to deal with the ileostomy and the sooner life returns to normal.

The ileostomy was closed in the spring and I returned to school and football. I took Cipro[®] that summer and when I finished the course in the fall, I started getting sick again and missing both school and football practice. I returned to Calgary to see Dr. A. and my worst fear was, would I have the ileostomy again? I saw Dr. A. a couple of times and he thought I should have a temporary ileostomy again. I put it off, tried a special diet but I was getting desperate. I did not want surgery but nothing was working and I thought, well it will only be temporary again and four months is not too bad. I saw Dr. A. on Halloween; he admitted me and I had surgery on Sunday.

I took a few days off before returning to school. I really wanted to play football and had to figure out how to play with an ileostomy. I had lost a lot of weight and was really out of shape, but I wanted to try playing. My parents found someone in Calgary who works with team sports. I saw him and he made a specialized body cast to protect the stoma. The first time I was scared as hell! Would I tear or damage something? The first time it was painful but a couple of days later I tried again and I slowly got used to wearing the cast. I played a full season. Everything went well, the pouch never leaked

but the stoma was very red and I worried. I called Dr. A. who assured me not to worry, just watch it. I learned how to deal with the ileostomy and altered my diet to decrease bowel activity around game times. I also took Imodium® to help slow the bowel activity.

As soon as school finished, Dr. A. closed the ileostomy. After recovering from surgery everything was actually functioning fairly normal. Then I started having pain in my back that I reported to Dr. A. but everything was looking good. The back pains got progressively worse over the summer but the ileoanal pouch was doing really well. Labor Day weekend I went away with my parents, I was in absolute agony and we came home early. Dr. A. was away so we phoned our family friend who admitted me to hospital and found Dr. A. who came to see me. The doctors thought I might have an abscess possibly involving my spine and I had x-rays, scans and an MRI. Dr. A. visited me after the MRI and told me I had an abscess. I thought, oh good, I will just get some antibiotics and be fine. But no, Dr. A. thought the pouch was causing the abscess, was very concerned about my spine and said I needed immediate surgery. He also said a neurosurgeon would be part of the operating team in case my spine needed stabilizing with screws. That was a huge shock. Suddenly the ileostomy did not seem quite as bad as having crushed vertebrae. My mom came in, I was crying and unable to tell her what was going to happen. Dr. A. explained everything to her.

So I had the ileostomy again and my spine was not as bad as they thought initially. I was discharged on a three-month course of IV antibiotics. At this point I was a year behind in school. I was trying to catch up with my courses, looking after a central line, wearing a fanny pack for the computer and antibiotics and adjusting to an ileostomy

again. It was a pretty tough time for me. After six weeks I returned to Calgary for an appointment with Dr. A. I had a pouchogram, the pouch was healthy and the infection was gone. We talked about the ileostomy and made the decision to leave the temporary ileostomy in place. The good news was I returned to school without the central line.

At the end of the school year I saw Dr. A. again and we talked about closing the ileostomy. My strength was back, I felt well again, and had the opportunity of playing in a junior men's league. I just wanted to go out with my friends, play sports and relax. I did not want another summer of surgeries and I was starting to realize the ileostomy did not affect me that much and it was still considered temporary. I worked out hard for football and the stoma prolapsed. After that the pouches frequently leaked so I had surgery to fix the prolapse. Following that surgery, I started having episodes that felt like blockages. The worst one happened at a friend's cabin out in BC lasting about 14 hours. That scared me; there was no close medical help. I returned to Dr. A. and he ordered a barium swallow that showed nothing. In the fall I returned to school and continued having these episodes. I had more x-rays and a trouble spot was found. They tried dilating the bowel at the point of obstruction but things got worse and I was getting sicker. I asked to be transferred to Calgary. Dr. A. operated and found scar tissue pinching the bowel and causing the blockage episodes.

Last summer I saw Dr. A. and another pouchogram was arranged. Only about a quarter of the required dye could be instilled into the pouch. While they were attempting to instill the dye, I was in agony and felt sick. Dr. A. consulted with colleagues in Cleveland and everyone felt the pouch would be impossible to use. Some options were given to me to consider. I could have another pouch made but I would probably have a

short gut and I already had problems maintaining my weight. I tried twice to use the ileoanal pouch and it was not successful. I pretty much decided to keep the ileostomy. At some point in the next couple of years the pouch will have to be removed. I think there is a cancer risk if it is left in place but I am going to prolong surgery as long as possible. I am on a new team, enjoying it and would like to play a couple of seasons with the team before missing time.

The bus rides to games in other towns can be very stressful. The bus does not have a bathroom. Sometimes I wonder if I am going to make it to the next town. While playing a game usually there is not time to use a bathroom and it can be a little stressful. I learned to manage my intake and take medication to slow things down so I can focus on the game and not worry about the pouch. When we are on the road four of us usually share a room. Four guys sharing a room and one bathroom is interesting! I need more time than everyone else and I used to find this especially stressful when I joined a new team. I don't get too wound up about it anymore. If something happens, it happens. I always hope nothing will happen but if it does, there is nothing I can do about it.

I do not mind talking about the ileostomy with my friends but it is difficult to tell people. If it is someone you are intimate with, it is very difficult. I avoided dating seriously for some time, but I met a girl about two and a half years ago. She had never heard of an ileostomy. That conversation with her was the hardest thing I have ever done. How do you explain an ileostomy politely and make it sound like it is not a big deal? I think the conversation was tough for her too but she took it very well. The ileostomy did not really faze her and that told me she was a quality person and I would like to be with her. I think when you tell someone; you know right away what kind of a

person they are, where they are in your life and how much you mean to them. Some people really freak out and others get totally disgusted but I have met very few people who react in those ways. I have met some very positive supportive people and this has been very good for me.

Sometimes I have skin problems but I change the ileostomy pouch fairly often and generally the skin heals quickly. If the pouch seal starts to loosen, sometimes I panic and wonder what I would do if the pouching system stopped being effective for me. When I found out there are lots of options, I felt better.

I think it is very helpful to meet people who have gone through the surgery but you have to be close in age and in the same situation so you can relate to each other. It would be helpful if the United Ostomy Association had more volunteers covering different ages. It is still going to be difficult adjusting but if you talk with someone first hand, it makes a big difference. In the beginning the stoma was temporary and I think it was easier for me because I kept thinking, I can do this for a little while. There was not the same shock factor. I do know if I had been told in the beginning the ileostomy was permanent it would have been much different for me.

My family and friends are very supportive and my friendships were not affected. My friends tend to worry and look out a little more for me but we picked up where we left off. I know this might sound cold but it is not like I am in a wheelchair and everybody can see something is wrong. This is something I can hide and it is really up to me if people know. I have the ultimate control of telling people.

The first few times I changed the pouch it was disgusting and it took a lot to get used to the care. At the beginning I was kind of fragile and the ileostomy was gross to

me. It was obvious to me some of the nurses were disgusted by it too, which made adjusting more difficult. If a professional nurse was turned off, I thought it must be really bad and I became more upset. I wondered how my friends and other people would react. I think some nurses do not realize how traumatizing ileostomy surgery is. Also the nurses deal with ileostomies every day as part of their work and they forget about the patient who has the ileostomy for life. I wonder about the people [nurses and doctors] who give advice and teach and have never experienced an ileostomy themselves if it would it be helpful for them to wear a pouch for a while? I wonder if that would make them realize how difficult adjustment is for us and give them a better idea of what having an ileostomy might be like. However, I do not think it is the same unless you actually have an ileostomy and the worry and care associated with it.

I had some pretty good challenges and adversities to overcome. At one time I never thought I would be at this stage. Looking back, you might not think this was a big deal but it was hard for me. I did not believe I would ever play football again or graduate from university.

Edith's Story

Edith is 35 years of age, single and employed by a communication company. She is a tall and slender lady with long blond hair, a wonderful smile and exudes lots of energy. She shares a town house with a friend and several pets. Edith suffered with chronic constipation for approximately 15 years. She chose to begin her interview with her past.

My problems started when I was about twenty years old. I thought I had the flu but my mother noticed I was losing weight and took me to our family doctor. I was also having a lot of rectal pain. I was admitted to hospital and surgeons found a large rectal abscess, which they drained and left to heal from the inside out. More abscesses occurred and then fissures started developing. The surgeons in my hometown recommended a second opinion in Saskatoon to help in determining the cause of the abscesses. The surgeons in Saskatoon recommended a surgeon in Calgary because now I was also developing fistulas. I could not go to the bathroom either [constipation]. I tried not to strain but after ten to seventeen days you have to get that out. My stomach would be very distended, as hard as wood and very painful. I had different outfits to progress along with the abdominal distention, as time between bowel movements got longer. Actually, I wore overalls most of the time.

I flew back and forth between Calgary and home frequently. I flew to Calgary, had surgery for the abscesses, fissures and fistulas and flew home. In 1997, I decided to move to Calgary for health reasons and my brother and many friends lived here. Dr. S. thought the only possible way I would heal was to have an ileostomy. When he told me what an ileostomy was, I said, "Absolutely not!" So he continued doing surgeries. In addition to the existing problems, bleeding hemorrhoids developed. Dr. S. injected and banded them but I continued bleeding and at one point my hemoglobin dropped to 86. I had surgery for the hemorrhoids and the bleeding stopped. I took oral iron and had IV iron and I am sure that contributed to the constipation problem.

Dr. S. moved and he recommended Dr. A. The bowel problems got worse and worse. Dr. A. ordered many different tests and one demonstrated my pelvic area

contracting instead of relaxing while trying to have a bowel movement. He was very concerned and more tests were done to try to determine the cause. I had 13 weeks of biofeedback with no improvement. I was bleeding again and passing blood clots. I was referred to two other doctors to try and determine the cause of the constipation. The option of an ileostomy kept being raised and I was totally "no". I thought, we can fix this, I can do this, and an ileostomy is gross and smelly. I did not really have a clue what an ileostomy was. I knew about having a bag and thought my intestines would hang out of my side and into the bag. I never saw a picture of a stoma and I received no written information. But I did not do any research either so I was at fault too. I totally fought it. I did not want an ileostomy. Looking back, I was very ignorant on the subject.

There were many times before I had surgery that I did not eat. If the bowel was already full, there was nowhere for food to go and if I forced myself to eat, it just came back up. It [stool] got so compacted down there [in the colon] and I did not want anything to blow up. About a year ago when Dr. G. was doing tests on me, he phoned me early one morning and he was in a panic. He told me to go to the Foothills emergency immediately to meet him. I had not brushed my teeth or anything, so I started getting ready. He phoned back to see if I had left and told me that if I did not leave away he was sending an ambulance. I guess I was so distended he thought I would blow a hole in the intestine. I spent the next nine hours or so in emergency until the bowel was cleaned out.

Last December I had another colonoscopy and this time multiple ulcers were seen in the colon. My family doctor again advised me to have an ileostomy. The ulcers scared me and I returned to the surgeon. He told me he could operate so the ileostomy

was reversible, however he would not consider the reversal for at least one to two years. I said, "Okay." The surgery was done laparoscopically and he inspected the entire bowel. He did not like the appearance of the lower intestines, however he did not remove any bowel because he promised he would not. I know now the colon has to come out. There is one bonus. I will never get colon cancer so there is always a positive side to everything.

I was in hospital for nine days because I had complications. The ileostomy was perfect but I had other problems. The first night after the ileostomy surgery I had an IV morphine drip and I did not feel quite right. In the past I had trouble with morphine and I had told someone when I was admitted. Dr. A. told me a goal after surgery was keeping me free of pain. The pump was not working and the nurses kept telling me it was. But it wasn't and I was in severe pain. My mom who is a nurse was with me and she went to the nursing desk and spoke with someone. After my mom spoke with someone, the nurses manually double dosed me to control the pain and continued manually giving me morphine. Apparently about four in the morning my phone was ringing and someone came to check. Later my sister told me she phoned because for some unknown reason she was worried. I woke up much later with nurses and doctors yelling at me. They worked on me for four or five hours and when I woke up they told me my respirations had increased to 5 a minute. When the next shift of nurses came on, they said their job was keeping me free of pain and breathing!

I knew something was wrong with my IV because I had many in the past. Sometimes IV's are uncomfortable but this felt wrong. My arm was at least two times the normal size and I saw green around the needle. I kept telling the nurses and they said,

“It is so hard to start IV’s on you, lets just play this out.” When the Dr. made rounds, he took the IV out and infection poured out. So I had another IV in the other arm for antibiotics and my arm did not get better. I had an ultrasound, a blood clot was found and I stayed a few more days. Mom returned home because she was working but many friends were with me all the time. At the end of the summer Dr. A. wants tests done regarding the blood clot because now I have a major risk factor for further surgery.

I give the utmost compliments to the nurses except for a couple. I question why stuff like my IV and breathing happens? They did not listen to me. The nurses checked my temperature and other things but never my abdomen. I asked to see a nutritionist and someone who lives with an ileostomy. Neither happened. My first meal consisted of beans, cauliflower, broccoli and meat with gravy. I could not eat it. The nurses were too busy to get something else so I did not eat. After that my brother brought my meals.

Prior to surgery I connected to the Internet and tried to learn everything about an ileostomy. I phoned an appliance manufacturing company, asking for information and they sent me videotapes and written information. I read everything I found. I met the ET nurses prior to surgery and a site was chosen for the stoma. I kept re-marking that spot and even put arrows pointing to it so Dr. A. wouldn’t miss! My ET nurses were amazing, answered all my questions, and addressed my comments and concerns. It was such an easy adjustment. They showed me once how to change the appliance and after that I did my own care. I did not want anyone else changing the pouch. When I got home I was going through about three bags a day because blowouts were occurring and I was changing everything. I thought I was doing something wrong then I tried a different

sized appliance and it has been perfect. The pouch is easy to change, except when the stoma is active. That is a bit interesting!

Since having the ileostomy, I am so happy. It [ileostomy] is amazing and I am disappointed in myself. I wish I had exhausted the avenues sooner, but I had to be mentally prepared and exhaust every possible avenue before consenting to surgery. I never want to look back and say, "What if." My whole life has changed. I have always had great family and friends but was never in a relationship. I never felt good, I was always exhausted and my energy was expended to working. The companies I worked for have been amazing, giving me time off whenever I needed. I graduated from University but I never lived. I existed and had no social life or career goals. Since April 8th I am starting to live again. I call my surgery my re-birth. Before I was sick I participated in sports and this winter I want to try downhill skiing again.

I never wanted a relationship because I felt I was not a whole person. Since moving to Calgary I have shared accommodation with a long-time male friend from home and he has been a huge support. He sat back and supported me emotionally and health wise. It took me a long time to let him in even as a friend but since my surgery, we have started dating! When I got home from hospital he asked to see the stoma, so I showed him. When he saw the stoma he said, "She looks good!"

I plan on returning to school in September and continue working part time. Before surgery, I never dreamed of returning to school. I am going to take an esthetics course and plan to offer services to patients in hospitals that routine nursing care often does not include. I can remember all the times I wanted my hair washed, nails done or a massage. I never had enough energy to do these things and the nurses either did not offer

or were too busy. I would also like to volunteer to talk with people having ileostomy surgery. I tell everyone about my ileostomy. If I had a wooden leg I would not wear pants all the time to hide it so who cares if the ileostomy pouch can be seen. If anyone is rude or says it is gross they own the problem, not me. We all go to the bathroom, mine is just a little more out there and is much more convenient for me. I have named her "Ellie". It is time for me to start living.

Frank's Story

Frank is 35 years of age, married, and has an infant son. He owns a construction related business. Frank was diagnosed with proctitis and colitis 17 years ago. He invited me to sit in a comfortable area adjoining the kitchen with a fabulous view of a green area. Frank is small and wiry in appearance and seems to abound with energy. He commenced the interview with his past history.

When I was seventeen I went on a cruise to Mexico and I did not eat very healthy, being on holidays. One day I passed a large amount of blood so I saw the ship's doctor who told me I had hemorrhoids. After returning home the bleeding did not stop and my doctor thought I might have a parasite. I was referred to a specialist who diagnosed my problem as proctitis. I took prednisone but the proctitis did not improve and for four years it was bad. Then I quit my high stress job of managing a restaurant, and had a complete remission for five years without the aid of medications. I ate and drank what I wanted. After five years I started a couple of businesses adding stress to my life and the symptoms returned. I took prednisone and Salofalk[®] and I was up and down.

I was referred to another specialist who did another scope and he found some colitis but did not think a surgeon would touch me. For about two years I took antibiotics and steroids on and off putting me into remissions. My bone density became borderline and the steroids were stopped. I also have a hereditary protein C deficiency causing a blood-clotting problem. While researching I found a certain type of colitis that fits with this deficiency and I spoke with my family doctor who dismissed the idea. He sent me for a barium enema that showed the last half of my colon as a little straight tube and covered in spots. My doctor told me my colon was not the greatest but neither was it the worse he had seen.

I decided to go to the Preventive Medicine Center (PMC) and the doctor I saw thought I was close to having my colon removed. I had read a lot of articles about heparin helping colitis and the doctors at PMC thought heparin might help and prescribed it. Within five days I was in complete remission. However the doctor looking after the blood clotting disease freaked out. She agreed heparin could help ischemic colitis but no one knew for sure what I had. I thought heparin was worth trying.

The colitis started coming back. I would be fine one day and a mess the next. I was up and down emotionally and I just could not take being sick any longer. Of the past seventeen years, seven years I was in remission and ten years I had full-blown disease. I had more tests done and yeast infection was suspected. I started taking a special drink to eliminate the yeast. This was the week of Christmas last year. Everybody, my mom, sister and aunt were trying to find solutions. At first, I was going to the bathroom at least every hour. This regressed to every half hour and then every fifteen minutes, twenty-four hours a day. It was unbelievably painful. I was also throwing up and almost passing out

each time I went to the bathroom. I was never sure which I was going to do. The pain was constant - on a scale of one to ten about a six except when using the toilet and then the pain was twelve out of ten. I lost 25 pounds and was in and out of hospital receiving IV's for dehydration.

One day my aunt, who had found a special doctor in California, was telling me to phone him and I said, "That's it, I am going for the operation." I phoned my parents to tell them and everyone tried talking me out of surgery but I had made up my mind. My wife called an ambulance but I was scared to leave the bathroom. I made it to the emergency without being incontinent. The doctor in emergency was from PMC and knew me. My next-door neighbor, a nurse, knew and phoned the colon and rectal surgeon, Dr. S., as I was leaving home in the ambulance and he visited me in emergency. She told me on several occasions that he was excellent and his visit made me feel good.

In the past I was told I was not a candidate for the inside pouch but Dr. S. disagreed. I was admitted from Emergency but not strong enough for surgery and for ten days I had TPN and Demerol® for pain. It was so nice to relax and have no pain. I was really upset about the lack of information available on the different bowel surgeries. I wanted to know all the pros and cons of the options and started asking questions. The ostomy nurse lent me one book, which was the only information they had. I normally do not read but I read that book in a few hours.

I talked with other patients on the unit and discovered I was the only one wanting a permanent ileostomy. Everyone else wanted the internal pouch. I searched the Internet and that is the only place I found information. I searched the Internet after I got home too. Every day Dr. S. tried to talk me into having the pouch. I kept saying, "No, I

want the easiest thing to live with.” He was making me mad because I felt he was pushing me to have the ileoanal pouch. Every day he questioned me about having the permanent ileostomy rather than the ileoanal pouch. I had two volunteer visitors; one with an ileostomy and one with the interior pouch. The person with the pouch went to the toilet twelve times a day, could not eat a lot of different foods and had to use cream on his rectum because it was always sore. I asked him why he had the pouch. He said that he could not have looked at himself wearing a bag. The man with the ileostomy was happy and had no restrictions. My decision was made.

I was really upset because all these people were having the pouch and I felt they did not know what they were having and no one was telling them. There was no available information on the procedure. My wife went to the library and information was hard to find. I had been sick for so long and it was really hard on us. I knew I did not want the internal pouch. I could not take any more. My son always looks for me in the bathroom and that bothers me. I do not want him remembering me sick and always in the bathroom. I told the surgeon, “Give me the stoma; that is the easiest.” I did not care at that point what it looked like but fortunately my stoma turned out to be perfect!

The night of my surgery the clicker giving pain medication into my back stopped working and no one could get it working. The pain was unbelievable. A doctor visited at midnight and gave me a shot, which did nothing. I was freaking out. I could not believe I was in a hospital, in pain and nobody could do anything! My pain was ten out of ten on the pain scale. The doctor said he did not know what to do and could not give me another shot because the accumulated effect could kill me. I asked if I was going to die and the doctor said he did not know. I was also concerned if the severe pain would interfere with

the healing process of my body and asked the doctor. He did not know. I was freaking out. I called my cousin who is my best friend, he came, sat with me, tried to keep me calm and helped me breath. I went the entire night with nothing for pain and thought I was going to die. The pain was unbelievable. I have never told my wife or parents. A nurse came in at eight thirty in the morning, started an IV and gave me morphine. She became my favorite nurse because she was the only person who helped me. For the following three nights I dreamed I was being tortured. Different pain medications were tried but I continued to hallucinate and was totally out to lunch.

One thing I discovered was if the nurses were late bringing pain medication, I never got caught up, and it always seemed to happen at night. In the daytime you can live with the pain, but not at night. I hated the nights. Some of the nurses were great and others just did not seem to care. It was almost a week before I started to eat. The dietician visited and said, "Eat as much as you can." Stupid me, I forgot I had not eaten for about two months so I ate and ate. Then I started throwing up. I had lost ten pounds since admission, was very skinny, and was so hungry. Three weeks after surgery I knew I would rather die than go through that experience again. I do not have a problem with dying.

The ET nurse came to see me after surgery and I had no idea what she was saying. One day I tried changing the pouch before she came and at first she was angry with me but after she laughed. It was a big shock having the rectum sewed shut. I do not recall anyone explaining that would happen.

After discharge I slowly got better. I do not ever remember feeling as good as I do now. I eat everything, chew well and have no problems. I could not be happier and

get along fantastic. I no longer look for the nearest bathroom; I empty the pouch about four times a day. I cannot believe people live with colitis when they can have an ileostomy. I tell everybody I know. Why should I hide it? I showed all my visitors while I was in the hospital, I wore a clear bag and they could see through it. After I got home if somebody had not seen it [the stoma] in the hospital, I showed them. I feel more comfortable that people know.

When I actually look at this thing and think you know, man, this is going to be here for the rest of my life, it sometimes bothers me, on a scale of one to ten probably a five at the worst. I think if I were single it would make a fairly big difference. I think it would affect me if I met somebody with an ileostomy. I am already married and it is a question of being healthy; nothing else matters. The ileostomy doesn't bother me; I make fun of it.

I use to be a very unhappy person and my family and friends see that now I am totally different. There is nothing to upset me anymore. I knew when I went into the hospital what I wanted. I made the decision with no doubt in my mind. I have to see both sides of everything, all the pros and the cons, weigh them out before making a decision. My mother does not think it is bad but my dad is bothered a bit. My wife has no problem with the stoma. We have been together since we were nineteen.

I do have skin problems. The pouch has leaked and my skin has been burnt. I tried a couple of different things and now use Durahesive[®], which seals tight against the stoma. Sometimes the skin is raw but it does not hurt and heals itself beneath the wafer. In the beginning, I had frequent phantom sensations of having to use the toilet but this is

improving. I have problems with bladder function but I am slowly returning to normal.

Everything is fine with sexual function. [His wife is expecting their second child].

I actually enjoy work. The couple of times I thought I do not want to be at work, I tell myself that you could be in the hospital. I will never complain again.

Gloria's Story

Gloria is 37 years of age and is a tiny attractive lady. She is married and has a baby. She has a masters degree, has worked for a large city newspaper and is currently employed full time. She lives in area of the city that is very pretty and well kept. Her home has been completely renovated. Her mother was visiting looking after the baby so Gloria could focus on the interview. She suggested the interview take place in the living room, which was very neat and clean with baby toys in one corner. There is a history of colo-rectal cancer in her mother's family but no history of inflammatory bowel disease. Gloria was diagnosed with Crohn's disease following her ileostomy surgery. She chose to start with her past history.

I was about 13 and visiting my grandparents in the country and suddenly one day I passed a large amount of blood. I returned home, saw our doctor and I had a colonoscopy and it was decided I had juvenile polyps. For the next five years I had routine colonoscopies and polyps removed by a snare. When I was 17, I had a transverse colectomy because polyps in the transverse colon changed characteristics. I had a full recovery but starting suffering with constipation and occasional blood in the stool. I continued to be routinely scoped and proctitis appeared.

We had been married about six years and I had not been able to get pregnant, so we decided to try the in-vitro fertilization (IVF) route. Part of the IVF routine is the prescribing of antibiotics. I got diarrhea but the doctors were not concerned as this is a common side effect. But after three months the diarrhea was getting worse. Incidentally, my work was very stressful during this time. The diarrhea got progressively worse and I was getting progressively more ill. The IVF failed and in retrospect that was probably good. There was a delay in getting to see my gastroenterologist but he agreed with the diagnosis of antibiotic colitis. He said I did not have ulcerative colitis and prescribed steroids. The steroids made me mental. I was depressed, could not sleep, had night sweats, lost weight and the diarrhea continued. I went to emergency twice because of excess fluid loss. I was now using the bathroom 40 to 50 times a day and was taking ten Imodium[®] a day. I could only manage working a couple of hours a day. I was cold all the time. One night I took a hot bath and passed out on the bathroom floor. When I woke up I crawled back into bed and did not tell my husband.

My sister was getting frantic. She knew something was wrong. One day she phoned my husband at work and they took me into emergency. We were told to expect an eight-hour wait. I could not stand up by myself, so they took my blood pressure and I was immediately in a bed. However, I was not being seen by a physician so my sister phoned my friend, who was a physician there at the time, and she phoned Dr. G. who came immediately. My family was told my bowel had perforated; I was in septic shock and had tachycardia. They took my husband into a room and asked him what I would want if I did not make it. We had a talk about what I wanted to happen if I didn't make it. They wanted to admit me to ICU but there were no beds; this was the long weekend in

August so I was admitted to a surgical ward. The nurses were really mad I was on their unit and there was a big showdown in the hall between the doctors and the nurses. I ended up by staying and I was booked for surgery the next day.

We were told I would probably have an ostomy. I did not know anything about ostomies except it is a bag on your side. Surgery creating an ileostomy was the only option at this point and it was better than dying. When I got back to the unit following surgery I asked the nurse if I had an ostomy. She did not know. My husband took the covers off me and looked, and that is how we found out I had an ostomy. I had many questions and the ET nurse was new and feeling a bit uncomfortable.

The worst part of being in the hospital was the dirt. Syringe covers and stuff stuck to the floor for days. One day my mother washed the floor and my husband threw my slippers out because they were so gross. The priority was teaching me how to change the pouch. I was shown once and after that I was expected to do it. I was still very ill, could not stand on my own, I shook all over and cried. The shower stall did not have a chair or bench to sit on or any place to lay supplies. I was terrified I would fall. I was also terrified for the other sick patients in my room who tried showering by themselves.

I had serious questions regarding the nursing care and a couple of inappropriate remarks. I missed one doctor's appointment because by then I was being admitted. My husband tried notifying the office to cancel the appointment. Later one nurse said to us that if I hadn't missed my appointment, I wouldn't be in this boat now. She made it sound like it was my fault I was sick. That really made me mad. Another nurse jokingly said, "There will no more beach time for you, ha, ha." I thought to hell with you, I am going swimming. There is no reason why you cannot do what you want. My self-esteem

had taken a real blow and those remarks were most inappropriate and did not help.

Some of the nurses obviously knew a lot about ostomies but they either did not have the time or it was not their mandate to educate. I wanted to wash my hair and brush my teeth and no one seemed to have time to help. There was also a small group of nurses who seemed to be super pissed off that they were there [at work].

I was very ill and steroids caused a weight gain and loss of 30 pounds in four days. I could not walk, the skin split on my ankles and I could not stop shaking. As soon as the steroids were discontinued I started feeling like a human being. Up until then I was seriously questioning quality of life, if it [surgery] was worth doing or should I have just checked out. I was asked if I wanted a visitor, someone who lived with an ileostomy and I said, "Yes." The visitor was excellent and the best part of the ostomy education but I did not understand she was from the Ostomy Society. She had two babies, one after she had the ostomy and she answered all my questions. It was very hard trying to recover from septicemia and learning to deal with the ostomy at the same time. I had no time to mentally prepare for the ileostomy. I think it is different if you are ill with disease and have emergency surgery as opposed to coming to the decision over time.

In the beginning I was allowed only ice chips and the ice machine was broken. All of us in my room were allowed only ice chips and there were none. Finally my husband brought a cooler and everyday supplied us with ice chips from home. Then I was supposed to drink Boost[®] but there never was any in the unit fridge. Again, my husband and mother brought my daily supply. The nutritionist visited me prior to discharge and told me what I should not eat so a blockage would be prevented. I did not understand the blockage thing. I never had a blockage before, so why now? The visitor

told me she ate everything. The gastroenterologist told me something different than the nutritionist. I did not know whom to believe and I was terrified. I did not want a blockage.

Following discharge, we returned to the IVF process and a fibroid was found and removed. The doctors wanted to start the IVF process again in December. I had also lost 25 percent of my hair, which was humbling and I figured that was the last straw, what else is going to happen? I had had enough and we wanted a break from the medical stuff. We took a short holiday called a *not dead yet* vacation, and had a great time.

We had a wonderful Christmas and in January it hit me. I had missed a period. I used a kit left over from IVF and sure enough we were pregnant! We did not tell anyone for a while because of everything else that had happened. I remembered one of the doctors from the IVF program had an obstetrics practice and I made an appointment to see him. The first question I asked was if he had any experience delivering women who had ostomies. He said, "Yes" and right then I felt so much better. He had no concerns about the ostomy and I had no problems with the pregnancy. She was a big baby and after 70 hours of labor I had a C-section. I asked them not to push on my abdomen because I talked with many women with ileostomies on the website advising me not to let the doctors do this as this may contribute to stoma hernias. Everything was fine.

We had the baby on September 11 and in November I noticed a bulge around the stoma and it got bigger and bigger. I visited our family doctor who lined up some tests and referred me back to the specialists. I did not see the surgeon until May. I had a hernia. After the ileostomy surgery, no one warned me about lifting or explained a hernia to me. The surgeon suggested if the rectal stump was healthy the bowel could be

reconnected and he explained all the pros and cons of everything. In the meantime I had a support belt made.

I had more tests done and the rectal stump was full of Crohn's. Now I know the ileostomy is permanent. I did not realize how much I was hoping to have it reversed. Everybody else knew it was probably permanent and in my brain I knew it too but my heart was hoping. I have to decide about the hernia repair. We want another child. The surgeon fixes the hernia by moving the stoma to the other side. If I have another pregnancy and another hernia, we run out of sides. The hernia makes it very difficult to wear clothes. I am a size 14 on the side with the hernia and size 10 everywhere else. The hernia is just getting bigger and bigger and the support belt is not helping. The hernia and the Crohn's in the stump are depressing me.

The surgeon wants to remove the rectum, which is quite invasive and difficult to heal. I would rather they treat the Crohn's and leave the rectal stump alone. I have concerns about it being removed. I understand the uterus tips, intercourse can be painful, bladder problems can result and healing time is prolonged. I have talked with people who confirmed my concerns and my surgeon basically dismisses them. I also wonder what a pregnancy is like with a hernia present? No one seems to know the answer.

I named the stoma "Schneck" because no one knows what that is and this way my husband and I communicate in public about the stoma and no one knows what we are talking about. In the beginning I was terrified of going to work. The first time I had an appliance failure I was on camera doing a live interview. My receptionist knows me well and she could tell by the look on my face something was wrong and she sent in relief. It was everywhere! I did have a complete change of clothes and appliance at work. The

second leakage also happened at work but this time I came home to change. It is very unnerving to have the appliance leak and come unsealed from your skin.

After a while I started becoming more used to the ileostomy. My output is liquid and that concerns me. When I was thin my clothes were big and nothing was visible. Since the hernia the ostomy is visible under everything I wear. It is really difficult and I have many appliance failures now. I think we should be told before discharge about the full range of products, not just what is shown us in hospital. When I was discharged I had the longest bag, it came half way down my leg and I felt like a freak. If you could get a better fit before discharge you would feel less like a freak.

I was terrified to do my care when I got home. What if I did something wrong? I think I was pushed a little too much in hospital. I needed more time to recover from the septicemia before they started teaching me stoma care. It was too soon for me. The care is much easier at home because I have more room and counter space. Skin care really concerns me because the skin is always angry under the pouch. I found a lot of information on the website that I was never told in the hospital, for example, about deodorizers, blockages and travel tips. Once I have the necessary information I feel so much more secure. I was afraid to use the bathroom at work because of odor. Using deodorizer is comforting for me and I think the odor has improved. Gas is the hardest to deal with. Sometimes I walk very gingerly to the bathroom so the pouch does not explode. I have to empty the pouch about nine times a day and that seems frequent to me. I learned some of the best tips from an eight-year-old girl in Arizona on the website.

I told my boss and team at work right away about the ileostomy. If something happened I needed help to cover me. It was not too difficult. I am a very open person

and the person I work with closely is familiar with ostomies because her cousin has one. No one else seems to know what it is so I do a lot of explaining. I travel for my company and my first trip I went alone. I decided because I was alone I was going to try swimming, just to see, and it was fine. There are a lot of ugly bodies in swimsuits! With the ileostomy I do not have the same toilet panic when I travel.

I was feeling depressed following surgery and my family doctor thought my B₁₂ might be low because some ileum was removed. And sure enough it was low so now I need B₁₂ shots. No one had mentioned this possibility. My family doctor is very thorough and she keeps a close check on everything. She is the one who told me my pathology. She read the report to me. The findings were consistent with Crohn's and the bowel had perforated causing the septicemia.

This illness and surgery brought my husband and me closer. He has been excellent. The ostomy is not an issue for him as he still finds me attractive and just wants me to be healthy. We want another child but we may not be able to. Just now I want to stay at home with our baby, be selfish and have time with her. There is lots of time later to work.

I cannot imagine if I were single what dating would be like. I think it would take a lot to overcome your body image and try forming a relationship with someone. When and what do you tell them? For some men and woman physical appearance is extremely important and body image needs to be part of ostomy education. Number one is recovering and adjusting and number two is body image. I talk with older women on the websites and body image is an issue for them too. They do not see themselves as the same person as they were before surgery.

Each step is terrifying but after I do something once or twice I know I can cope. I have learned a lot off the websites. I am always worried, wondering what may happen next. I compare myself to my fit, active, young, professional friends and think about the ileostomy every day and wonder if I could have done something different.

Summary

The stories of the participants have been presented as spoken in their own words and open a window into their lives. Although each story was unique common themes were evident. Telling their stories gave participants the opportunity to unite the events around their lives, living with bowel disease, having surgery and living with a permanent ileostomy. These stories can serve as a primary means for understanding the lives of these young adults living with a permanent ileostomy. In the following chapter I present the analysis of the narrative and identify common themes and differences.

CHAPTER FIVE

ANALYSIS OF THE NARRATIVE

This study focused on young adults' stories around receiving and living with a permanent ileostomy. The shortest time since surgery was three months and the longest four years. The participants freely recounted their life experiences of living with a permanent ileostomy. For some participants the ileostomy was a cure for their disease and for others it was not. Ulcerative colitis affects only the colon therefore a colectomy with a permanent ileostomy is considered a cure. Crohn's disease on the other hand occurs throughout the gastrointestinal tract, from the mouth to the anus and a permanent ileostomy is not a cure (Black, 2000). All chose to tell about living with their disease prior to the permanent ileostomy; it is part of their history. For two participants living with the disease was more traumatic and threatening than living with the challenge of a permanent ileostomy.

Subjectivity is at the center of the storytelling process. The researcher may have subjective stances influenced by past experiences and the relationship and interaction with participants. While listening, transcribing and later constructing the participants' stories I found myself as an ET nurse connecting to their incidents and situations. Reflecting and analyzing the data, however, requires some objectivity and Atkinson (1998) warned researchers of the need for balance between subjectivity and objectivity when analyzing stories.

The purpose of this study was to hear the stories of young adults living with a permanent ileostomy and how the ileostomy has affected their lives. As I listened to their

stories and returned to the transcripts I gained fresh insights into their world of dilemmas, struggles and triumphs.

In this chapter I present my analysis of the participants' stories using the framework of Clandinin & Connelly's (2000) four directions of inquiry: inward and outward and backward and forward. These four directions are positioned in the three-dimensional narrative inquiry space of temporality, personal and social, and place (Clandinin & Connelly). The framework identifies the directions in which most storytellers probably move while narrating their stories. Backward is the past or history of the participant's lived experience and forward direction is the future, where the person is going. Outward direction refers to the conditions in the environment and the person's place in the world. Inward direction is the internal condition of the person such as feelings, values, moral disposition, aesthetic reaction and spirituality (Clandinin & Connelly, 2000). Researching an experience places the researcher simultaneously in all four directions. Within these directions common themes or patterns were identified as well as obvious differences.

This chapter addresses the second research question: what common and / or divergent themes can be identified across stories of young adults with permanent ileostomies? In order to identify common themes and present the analysis, I returned numerous times to the original transcripts to ensure I was remaining true to the narrated stories. The chapter begins with the biological characteristics of the participants.

The Participants

The participants were seven young adults: three men and four women ranging in age from 24 to 40 years. The majority were in their 30's (median age 34.5 years). Five participants resided in Calgary, one in Red Deer and one in Medicine Hat. Two of the female participants were married with children, two were single; one of the male participants was married with a child and two were single. Crohn's disease, ulcerative colitis and chronic constipation caused by autonomic insufficiency were the diseases necessitating the creation of an ileostomy. Five of the seven participants had lived with a temporary ileostomy prior to receiving the permanent one; several had temporary ileostomies and reversals more than once. Educational backgrounds ranged from high school education to a masters degree. All participants were employed.

Looking Backward

This section includes the lives of the participants prior to surgery, the immediate post-operative recovery period following the surgery and the post discharge period up to the time of the interview. Common or divergent themes were organized into four components that nursing care addresses: biophysical, psychological, social and spiritual (Deeny & McCrea, 1991). Spirituality is inseparable from biophysical, psychological and social; together they form the whole (Golberg, 1998).

Looking backward common biophysical themes clustered around the disease, post-operative pain management, nursing care and stoma concerns.

Enduring the Disease

Pervading each story was the struggle with the disease prior to surgery. In recalling their lives participants talked about the vicious cycles of exacerbations and remissions of their diseases. Participants endured their disease until either elective surgery was chosen or emergent / emergency surgery became imperative for survival. Several described a sudden onset of the disease, others had a more insidious onset, coping with the disease for years; several enjoyed long remission periods and others did not. The disease duration for the participants ranged from three to twenty-eight years (median of fifteen years). Most participants experienced pain associated with their bowel disease and for some, pain was always present. One participant took Tylenol #3[®] for over twelve years to help ease the abdominal pain associated with Crohn's disease. Other participants enjoyed pain free remissions.

Post-operative Pain Management

Mismanaged post-operative pain control left two participants wondering if they were going to die and convinced they could not endure a repeat experience. Frank described his experience:

It was unbelievable pain, ten out of ten on the pain scale. I was freaking out. I couldn't believe I was in a hospital, in this much pain and nobody could do anything. So I sat there the entire night after my ileostomy with no painkiller. A doctor at midnight gave me a shot in the back and left. The nurses said they couldn't do anything else until the doctors came in at 8:30 in the morning. My

cousin, who is my best friend, came in to help calm me and help me breath.

The pain was unbelievable and I thought I was going to die.

Frank recalls that the night nurses were always late with his prescribed pain medication, making him anxious due to the anticipation of increased pain. He said, *"You'd never catch up, in the daytime you could live with the pain, but at night you can't and a lot of the nurses just didn't seem to care. I hated nights."*

Another participant recalls her pain increasing despite using the pain pump, *"I knew it [pain pump] wasn't working and they kept telling me it was. I totally felt everything."* Eventually nurses manually administered the morphine by the pump, creating a respiratory crisis; she remembers waking up with doctors and nurses yelling at her. Later the staff told her that they *"...got me back to five breaths a minute."*

Nursing Care

Most of the participants reported that they received excellent nursing care and were very appreciative. Several participants had been hospitalized in different facilities and in more than one city. Despite recalling the nurses as being too busy with other patients to give him the necessary time to ask questions, Bob recalled: *"I had excellent care in all the hospitals."* Anne remembered when she started learning stoma care: *"The ET Nurse kept her hand on my shoulder and seemed to understand how difficult it was for me."* She also remembered *"...four nurses who stood out for me and managed to convince me that with time I could deal with the ileostomy and be fine"*. She especially recalled the empathy of one night nurse who helped her empty her ileostomy appliance.

Anne was crying and upset during the procedure and this night nurse remained with Anne for over an hour until she was calm.

Carol and Edith perceived that “ *most of the nurses were awesome*”, and gave “the utmost compliments to the nurses, except for a couple.” Edith related: “*My ET nurses were amazing, answered all my questions, and addressed my comments and concerns.*” Carol remembered: “*The stoma nurses helped me with the ileostomy, but the other nurses did not help or teach me.*” Frank recalled that his first post-operative night was especially painful as he did not receive analgesics. He remembered the nurse who gave him pain medication the following morning: “*She became my favorite nurse because she was the only person who helped me.*” Frank seemed puzzled: “*Some of the nurses were great, and others just did not seem to care.*”

Conversely, some participants perceived that the nursing care lacked quality and caring. Concern was expressed that nurses did not have time to answer questions or assist with what participants thought were standard components of nursing care. For example, they felt assistance with washing and bathing in the immediate post-operative period, delivery of pain medication within an acceptable time period, availability of prescribed nourishment, and education relating to the ileostomy should be aspects of nursing care. Carol recalled asking for help to wash - the nurse brushed her off, leaving the room. Thereafter her husband helped with her routine morning care.

Several participants’ families brought nourishment and meals. Gloria was allowed only ice chips for several days and she recalled that the ice machine was broken. Her husband brought a cooler from home and supplied ice chips for her and other patients. When Gloria was prescribed a nutritional drink, none was available. Her

husband and family brought her the prescribed nourishment. Edith recalled being unable to eat her first evening meal and never receiving a substitute. For the remainder of her hospitalization her brother brought her supper.

Gloria recalled the anger of the nurses when she was admitted to their unit instead of ICU: *"The nurses were really mad because I was too sick to be there. So there was a big showdown in the hall between the doctors and nurses."* She also recalled, *"A small group of nurses who seemed to be super pissed off that they were there [at work]"* and it seemed that she and other patients always had to request assistance as it was not offered. Once the participants were discharged home, they recounted other complications and challenges.

Stoma Care

Fear was associated initially with stoma care and appliance changing. Gloria said *"I was terrified I was going to do something wrong."* Gloria and Anne remembered shaking with fear while attending to their pouch. Bob recalled the shock of seeing his stoma: *"All of a sudden you have this small piece of colon [small intestine] sticking out of the stomach wall."* Carol felt more comfortable when her husband helped with her care. In contrast, Edith was independent following one demonstration of stoma care and felt the care was easy.

On-going pouch failures and leakage were recalled by six of the seven participants. Three female participants recalled having to return home from work to change their appliance and clothes. Anne and Carol recalled apprehension having to explain to their supervisors why they needed to leave work. However, their supervisors

required minimal explanation and were very understanding. Gloria recalled her pouch leaking while doing a live television interview, *"Thank God my receptionist knows me well and she could tell by the look on my face that something was up. It was very unnerving ... and you're always worried."* Doug felt comfortable at home; however, whenever he went out he was constantly fearful the pouch would leak. He would visit a bathroom every hour to check his pouch. Whenever he went out he just wanted to return home.

Two participants reacted differently to their stoma care. Edith experienced pouch leakage; however, she did not express fear of self-care and appliance management. She thought she was doing something wrong to cause the leakages and calmly solved the problem herself. It was interesting to note that Edith, who had her ileostomy the shortest period of time in contrast to the other six participants, voiced complete ease and comfort caring for her ileostomy. Bob was nonchalant regarding self care, choosing not to change the pouch even when he knew it was necessary: *"Gauze pad and some tape, tape it up and get another day's use out of it."* Bob also, at times, did not pay attention and allowed the pouch to become too full resulting in explosive leakages.

Stoma complications ranged from minor skin irritation to a prolapsed stoma and gangrenous bowel. Complications were recalled by six of the seven participants, the most frequent being peristomal skin irritation. Some participants regarded skin irritation as a major and on-going challenge. Some chose to consult with the ET nurse and others chose to successfully problem-solve for themselves. Doug phoned his surgeon for guidance.

Bob suffered a serious, possibly life-threatening prolapsed stoma and gangrenous bowel. The resulting surgery and necessary recovery time forced him to drop out of school. Two participants developed peristomal hernias. Gloria's hernia was very large and visible, requiring her to wear clothes four sizes larger than normal. She wore a support belt that did not work to reduce or contain the hernia. Bob developed both a peristomal hernia and several incisional hernias; however, he appeared unconcerned about these complications, treating them as just part of his life, *"If I did not have one [ileostomy] I would be six feet under ground."*

Two common themes pertaining to a psychological component related to body image and education.

Impact on Body Image

Negative reactions to their altered body appearance following surgery were evident across the stories. Participants spoke with emotion when recalling their personal feelings around their altered body appearance. Doug recalled viewing his abdomen the first morning post-operatively: *"I'd been working out and was in pretty good shape. I looked down and saw this, a huge scar, numerous staples in my abdomen and a bag hanging off my side. It just looked awful."* He remembered wanting to be by himself for a couple of days to deal with the impact of the ileostomy. Bob recalled, *"All of a sudden you have this small piece of bowel sticking out of the stomach wall. It was the shock of my life having a bowel movement [through the stoma]."* Both these participants had great difficulty discussing their ileostomy with women, stating *"The intimate issue is probably the worst part."* Doug purposely avoided seriously dating so he could evade explaining

his ileostomy to a girlfriend. Bob experienced a leak while on a date and remembered his girlfriend “*freaking out.*” The incident ended their relationship. Although Anne had had several serious relationships she remains single. She felt the presence of the stoma may play a part. She said, “*The stoma is ugly and I am damaged goods.*”

Three married participants felt having an ileostomy would have impeded dating and forming relationships if they had been single. Frank said, “*If I was single it might make a fairly big difference. It would affect me if I met someone who had this.*”

Although his marital status was secure, having an ileostomy bothered him at times; “*...on a scale of one to ten probably about a five at it's worse.*” Gloria, who was married, said she felt like a “*freak*” and thought it would be a major adjustment “*...to overcome your body image and try to form a relationship. I can't image if I hadn't been married what dating would be like.*” She was glad physical appearance was not important to her husband. However she continued comparing herself to her friends who are, “*...fit, active and young and I think about the ileostomy every day and wonder if I could have done something different.*” In contrast, Edith, who is single, felt positive about her body image following surgery. For the first time in many years she wore “*normal clothes and not overalls*” that she used to wear to hide her distended abdomen.

Five of the seven participants spoke about the desire to conceal their ileostomy both physically and socially. Three female participants spoke of the challenge around hiding the appliance in their clothes and voiced distress that at times the appliance was visible. Anne recalled the effect and distress of her weight gain:

Before I gained these 20 pounds, I could hide it a lot better. Now it is more pronounced when something is in the pouch. I'm emptying the pouch about every

hour to two hours, because as soon as it gets a little bit in there, I can see it and I can't deal with it.

Gloria had a large peristomal hernia making concealment of the ileostomy nearly impossible, *"It didn't show in my clothes until I got the hernia. I was so thin and my clothes were so big. Since the hernia it shows in everything I wear."* She established secret communication with her husband in case she needed to speak with him in a social setting regarding her ileostomy. Carol said she told few people about her ileostomy and her sons had not told even one friend. She was pleased to find clothes designed especially for people with ostomies, which help conceal the pouches.

Bob explained, *"I have to wear a lot of sweats and I wear jeans only in the wintertime so I can wear a baggy sweater and hide the pouch."* Doug, the youngest participant, spoke at length about whether or not to tell people that he has an ileostomy:

I saw somebody in a wheelchair and I think this sounds cold but I said this person has something where everybody sees and knows. At least I've got something I can decide to tell them if I want. Nobody has to know. It is up to me if people know or not. This is something I can hide.

In contrast, two participants were totally open about their ileostomy. Edith compared having an ileostomy to having an artificial leg: *"Would I wear pants all the time? Absolutely not, so if the ileostomy bag sticks out who cares? If someone is rude about it, they own the problem and can leave."* Frank showed all his visitors his ileostomy while in the hospital and also later at home and said that almost everybody looked.

Need for Information and Education

The lack of available written information was frustrating and viewed as a deterrent to adjusting to living with an ileostomy. Three participants searched the Internet and obtained most of their post-operative information from websites and chat rooms; Gloria remarked, *"I learned some of my best tips from an eight year old girl in Arizona."*

The need for written information reached back prior to surgery as well as following surgery. While in hospital waiting for surgery, Frank received a book from the ET nurse; however, he wanted more information and asked his wife to go to the public library. He remarked, *"As soon as I got out of the hospital I was on the Internet looking to see what I could find."* Edith, in addition to researching the Internet, also phoned an appliance manufacturer pre-operatively and received videos and written information applicable to both pre and post-operative teaching. Gloria summed up her quest for information post-operatively, *"No one could actually explain it [blockage] to me [then] I started reading stuff I found on the website and I learned all that stuff [traveling and general tips] on the website."*

Disappointment was expressed at the lack of education offered by the nursing staff: *"Some of the nurses obviously knew a lot about ostomies but they just didn't have the time or it wasn't in their mandate to do education."* Carol received no written information regarding ileostomy management or suggestions for daily living concerns on discharge; however, she received a large amount of written information and a video from the home care ET nurse. Five participants strongly believed in being self-educated regarding surgical options and disease processes and suggested that all patients should do their own research.

Common themes looking backward across the stories were related to the disease, post-operative pain management, nursing care, stoma care, body image and education. I found the stories of mismanaged post-operative pain disturbing in today's pain management environment. I also found it difficult to hear the stories of perceived lack of empathy and caring on the part of the nurse, given the advancement of nursing education in recent years.

Looking Outward

Outward experiences refer to the conditions in the environment and the person's place in the world (Clandinin & Connelly, 2000). Looking outward centered on the common themes of encountering and connecting with people, social and work roles. In this section I will examine the reactions of people to the ileostomy beginning with nurses in hospital.

Nursing Attitudes

Doug and Gloria perceived negative nursing attitudes regarding the stoma care. Doug recalled a nursing attitude that was especially traumatic for him:

Obviously some of them [nurses] were disgusted by it [ileostomy] and they are professionals in the area and if they seemed turned off by it, it must really be bad and you think this must be worse than I thought. When they didn't seem totally fine with it, it started to bother me. I wondered how is someone outside of the hospital going to react? Some of the nurses didn't realize how traumatic the ileostomy actually was for me.

Doug wondered if nurses became complacent over time caring for patients with ileostomies: *"It seems like some people [nurses] forget this is your first time and it is pretty hard on you and obviously it takes getting use to and emotionally it's very draining."* He felt nurses doing his ileostomy care forgot that it was he, the patient, experiencing this traumatic event. He acknowledged that, *"Some nurses handled it better than others and made it seem like it wasn't a big deal [making having an ileostomy more] comfortable for me."* Doug said that he often wondered about the people who give advice around living with an ileostomy but have never had to live with one. He thought:

It would probably be helpful for them to wear a pouch with something in it, it wouldn't be the same but maybe the experience might make them think how complicated and difficult it is. That it is a big adjustment and takes a lot to get used to.

Gloria recalled the insensitive attitude displayed by a young nurse trying to joke about the ileostomy: *"Ha, ha, ha, no more beach time for you. Like she was trying to make it seem like it was not a big deal and I thought to hell with you."* She wondered why this nurse was telling her that she could not do things when she believed her life was going to be better.

Other Encounters

Doug encountered situations where people reacted negatively to the presence of a stoma. Doug said, *"I've met a few people who were disgusted and grossed out by the ileostomy but fortunately I have not met very many."* He quickly learned to assess people by their attitude, where they were in his life, and if he wanted them in his life.

Bob said he is fine socializing with his male colleagues because it is a “*guy thing*” but has great difficulty socializing with women.

Connecting With People

All participants said talking with someone who experienced the same surgery enhanced the adjustment to living with an ileostomy. Those participants who had a visitor from the Calgary Chapter of the United Ostomy Association (UOA) found it was a valuable part of their education, with one exception. Doug, a young single male, could not relate to his visitor, an older married man. Although Doug did not gain by the visit, he nevertheless recognized the value.

Gloria felt that the visitor was the most valuable part of her ileostomy education. It was her visitor who answered all her questions and addressed her daily living concerns. Frank’s two visitors each had a different surgical procedure, confirming for Frank that he had made the right surgical choice. Some of the participants sought other means of interacting with people living with permanent ileostomies, for example, logging onto website chat rooms.

All participants valued and learned from interactions with other people who experienced similar surgery. Five of the seven participants expressed the desire to become involved with the UOA support group. Doug said, “*No one can understand it the same as someone who has lived it.*”

Family Relations

The support of family and friends was evident throughout all the stories.

Participants spoke of spouses and families helping them with physical and psychosocial recovery, thereby playing a crucial role adapting to living with an ileostomy. The married participants seemed secure in their relationships. One married participant said, “... *this [ileostomy] brought us closer together if you can believe that.*” Carol stated that her husband was her best support in all steps of her illness, surgery and recovery. Edith had several friends move into her home to help her while she recovered from surgery. She never socialized outside of her home or formed a relationship prior to having the ileostomy because her illness consumed all her energy. Since surgery she is socially active and dating. Anne spoke of her parents and best friend supporting her through her disease exacerbations and surgeries and said her father “*has always been my rock.*”

Social and Work Roles

Participants recalled the trepidations around participating in social activities and returning to work. Doug felt safe at home but found socializing terrifying and wondered how having an ileostomy would impact his friendships. He recalled his first few nights out, “*I would empty it [the pouch] every hour just to check it. I just wanted to go home. I don't remember seeing the movies or the games.*” He remembered the difficulty seeing his friends for the first time, thinking something would be different; however, he soon realized relationships with friends had not changed. He was also terrified when he

resumed playing ball, *"I was scared as hell. What's going to happen? Am I going to tear something off or damage something?"*

Carol still declined dinner invitations with friends and her husband's colleagues and she was terrified to return to work, frightened of people looking at her and fearful of injuring her stoma. At the back of participants' minds was the constant worry associated with possible appliance failure and leakage. Gloria said, *"In the beginning I was terrified of going to work"* and expressed anxiety surrounding possible pouch failure and leakage in the future. Anne abandoned thoughts of returning to a modeling career and feels she will never marry and never have children. She was unsure if she connected these beliefs to having an ileostomy, her Crohn's disease, or a combination. Having the ileostomy changed her social patterns. Prior to having the ileostomy she did not participate in volunteer activities; now she wants to help people in similar situations. She participates in an annual fund raising event for research involving public speaking and talks with people in similar situations as herself.

Common themes looking outward were encountering and connecting with people. Participants, although fearful in returning to social and work activities, learned that relationships were unaffected by having an ileostomy. Perception of negative nursing attitudes seemed to leave a lasting impact on Doug and Gloria. Doug learned how to react when confronted with negative social encounters. Connecting and having conversations with people with permanent ileostomies was an important factor in adjusting to living with an ileostomy. Families and friends were the participants' best support system and played a key role in adjustment.

Looking Inward

Inward experience is the internal condition, the personal dimension of the person such as feelings, values, moral dispositions, aesthetic reaction and spirituality (Clandinin & Connelly, 2000). Common themes relating to this direction were the uniquely personal struggles related to the initial decision for surgery and the stoma.

Decision for Surgery

Participants recalled the struggle around making the decision for surgery following the suggestion of a permanent ileostomy. In their own way and for their own reasons some reached the ultimate decision to have a permanent ileostomy. For some a crisis forced the decision, for others it was an accumulation of incidents and crises and for two the decision was out of their control. Three participants had planned elective procedures, one participant had an emergent procedure and three had emergency surgeries.

Carol described her agonizing process of decision: *"I talked with my husband, myself, my Dad's preacher. I cried and I prayed for twelve months and finally thought it was right."* Edith had five years previously received advice that a permanent ileostomy would alleviate her disease symptoms but she refused to have surgery. Her symptoms progressed and in December 2002 multiple ulcers were seen on a routine colonoscopy: *"When I heard the word ulcers my mind changed 180°."* She visited her surgeon and surgery was booked. Bob recalled coming to terms with his disease: *"Enough is enough and something inside me knew it was the right thing to do."* After weeks of constant severe pain, diarrhea and trips to the emergency department, Frank said one night:

"That's it, I'm going for the operation" and his wife phoned for an ambulance. For Gloria, surgery was a life-saving procedure. She recalled the night her husband took her to emergency: *"They took my husband into a room and told him I might not make it and we had to have a big talk about what I wanted to have happen if I didn't make it."*

The Stoma

Participants objectified their stoma. No one referred to the stoma as "my" or "mine", preferring to name the stoma *"Ellie, Egor and Schneck."* Gloria named her stoma so communication with her spouse regarding the stoma could take place in a public setting but in a private language. Frank repeatedly referred to his stoma as *"this thing"* and Carol referred to her stoma as *"he."*

Most participants wished they did not have a stoma despite being physically improved with an ileostomy. Anne refused to have a proctectomy on the outside chance of being able to have the ileostomy closed at a future date. She expressed strong emotions of anger and hate towards her stoma throughout her story. Her hatred of the stoma had never wavered since the day of surgery. She also voiced anger over losing all her colon, part of the ileum and never having a remission in her disease.

Two recurrent themes looking inward were the decision for surgery and emotions directed at the stoma. Participants who were given the choice recalled the agony of the decision for surgery. For some participants the disease progression meant the decision was beyond their control. When referring to their stoma, participants did not acknowledge the stoma was part of their body. Anne was the only participant who spoke

of frank hatred of her stoma; however Frank's label for his stoma as "*this thing*" could be interpreted as similar.

Looking Forward

Forward direction looks to the future, where the person is going (Clandinin & Connelly, 2000). Looking forward participants focused on living. In this section I will present their anticipations and goals.

Renewed Perspective on Life

Participants had lost energy, the desire to participate in activities with family and friends, and for one participant the will to live. Gloria wondered, "*Should I have just checked out?*" Regaining and renewing energy and perspective on life was woven throughout their stories. Frank, who suffered vicious cycles of disease exacerbations and remissions for years prior to his surgery, feels he is a changed person. Prior to surgery because of his disease he was unable to enjoy family or his friends. He now embraces life, enjoying family, friends, work and life in general. His family and friends were very cognizant of the change, "*They can't believe I'm the same person.*"

Gloria, whose surgery was a life-saving procedure, suffered with depression while taking steroids after surgery, seriously wondered about quality of life and if life was worth living. Four months after surgery however, she discovered she was pregnant and "*I was ecstatic.*" She plans to have more children. For 15 years Edith lived with disease that sapped all her energy. Since her surgery she had renewed energy and was glad she

had the surgery. She described her new life, *"It's time to start living, not existing. I call my surgery my re-birth."* Carol who lived with disease symptoms for ten years, stated:

The best part of having an ileostomy is you live again. I think I am a fighter; I had the willpower to have the surgery and get on with my life for my two boys and husband. There are always things you can work around to make life wonderful. I am a better person now.

Bob planned to return to school, finishing a program he had left several times because of disease and surgeries. Doug summed up his feelings:

I have had some pretty good challenges and adversity to overcome. You might not think this is a big deal, but thinking back to how hard it was I never thought I'd be in this stage. I didn't think I'd be playing ball again and I have graduated from University. Things are back on track.

For three participants however, the future remains uncertain. Anne and Gloria, who have Crohn's disease, shared their worry of disease progression. Gloria feared future surgery and possible resulting complications. Anne feared the new drug, presently keeping her Crohn's disease in remission, would stop working. Despite this, Anne anticipated a promotion, increased her volunteer activities and was renovating her house. Anne said, *"I prepare for the worst, hope and dream for the best and settle for anything in between."*

Bob and Gloria wondered how their hernias would impact their futures. Gloria was concerned how the hernia would affect future pregnancies; Bob wondered if his hernias could be repaired. Several participants wondered if the integrity of the

peristomal skin would continue to be a concern. Doug and Gloria were fearful of their current appliance failing to meet their needs and that options may not be available. The fear of untimely pouch leakage remained with all the participants.

Despite fears and unknown factors, all participants had renewed energy for living. All participants trusted and hoped for the best. Participants recognized time was one of the biggest factors in adjusting to living with an ileostomy. A common theme shared by all participants was the renewed perspective on life.

Summary of Analysis of the Narrative

In this chapter of the research report I explored the stories of young adult women and men living with a permanent ileostomy. The four directions, inward and outward, backward and forward provided the framework of categorizing participants' lives. Common themes were placed within the biophysical, psychological, social and spiritual components of their stories. These components interact with each other and are not easily separable. This often made the placement of themes difficult.

Common and divergent themes were identified across the stories. Divergent themes seemed to be reflective of the surgery either being planned or unplanned procedure and the participants' input to the decision for surgery. All participants endured disease, some for many years before making a decision for surgery. For a couple of participants a life-threatening crisis forced the decision. Participants shared numerous common themes associated with their disease, hospital experiences, and social and personal adjustments to living with a permanent ileostomy. In the following and final

chapter I offer my reflections on the stories, messages for nursing practice and nursing researchers and thoughts on the method.

CHAPTER SIX

CONCLUSIONS

In this final chapter I present a critical review of the method and my reflections on the findings of the research study, implications for nursing practice and suggestions for further research. The purpose of this research study was to reconstruct stories of young adults living with permanent ileostomies and to identify common and divergent themes. The method of narrative inquiry provided an understanding of the unique experience and perspective of these individuals.

Reflections on the Study Findings

Two research questions directed the study: (a) What are the stories of young adults living with permanent ileostomies? and, (b) what common or divergent themes can be identified across the stories? These questions were addressed by informal unstructured interviews with seven young adult men and women. The interviews were audio taped and supplemented by field notes. Transcriptions of the taped interviews and the field notes were the data used for the study. The first phase of the analysis involved reconstructing participants' stories in their words. The stories are the subjects' interpretive accounts of living with disease and a permanent ileostomy. Readers can gain understanding by reading the stories and forming their own interpretation of the participants' experiences.

The second phase of analysis critically examined the stories for common and divergent themes. Themes were placed in the framework of the four directions of

narrative inquiry: inward and outward, backward and forward. These directions are situated within the framework of the three-dimensional narrative inquiry space (Clandinin & Connelly, 2000). Narrative knowing has a holistic quality; however, significant time periods instead of an entire life experience can be examined (Connelly & Clandinin 1990). Although the initial intent of the study was to listen to participants' stories of living with permanent ileostomies, it was apparent that the entire disease history was intimately connected to the subjects' living experience with a permanent ileostomy: the two experiences were inseparable. For some participants the disease constituted a large part of their story and for others a smaller part. Reflecting on the stories and identifying common and divergent themes, I recognized participants' strength and courage as they struggled with the disease, the decision and the adjustments.

No glamour is attached to having bowel disease and unlike heart disease; a silence surrounds bowel and ostomy surgery. Western society places a value on the "normal" body, which is productive, healthy and unblemished (Santos, 1998). The creation of an ostomy destroys a component of this "normal" person. This presents a challenge to young adults adjusting to living with an ileostomy. Participants in this study encountered few people who knew about ostomy surgery thus requiring explanation and discussion of their surgery at inopportune times. Open communication and public education is important to facilitate societal understanding.

Telling a story "... is not meant to be therapeutic" (Atkinson, 1998, p.12); however, telling their stories appeared to have a cathartic effect for some participants. Subjects recalled their experiences as if they occurred yesterday and an underlying sense of urgency was subtly apparent as if once started, they did not want to stop. This study

created the space to tell their story. Frank (2000) believed that stories help remoralize people following the demoralizing of illness. The following section will examine the data of the young adults in this study against the reported data in the literature.

Quality of Life

Study findings reported the majority of people generally adapted well to living with an ostomy and had a good quality of life (Awad et al. 1993; Kelman & Minkler, 1989; Kennedy, 1988; Macleod et al. 1986). Participants in this study presented similar findings to the majority of reported people in the literature. Pemberton et al. (1989) found regardless of how well adjusted a patient was or the degree of improved physical health, there was a desire not to have a stoma. This was a common theme related by six of the seven participants in this study.

In contrast, Karaday et al. (2002) stated that the impact of ostomy surgery is often underestimated in terms of the negative impact on quality of life. This statement is congruent with the feelings of several participants in this study who felt health care providers did not understand the impact of the ileostomy and the difficulty of adjustment. As young adults they felt a major impact from the ostomy surgery as their lives and their families' lives were interrupted. In hindsight, all the participants recognized that time was a major factor in adjusting to living with an ileostomy. This time factor was supported in research findings (Marquis et al. 2003). In addition, these authors found that confidence in self-care and satisfaction with care received from health care providers impacted quality of life. Some participants in this study voiced dissatisfaction with care received from health care workers. They perceived some nurses as not caring, lacking

empathy and not providing the nursing care they expected. Significant others compensated for the perceived lack of assistance from health care workers. Implications for nursing practice will be discussed later in this chapter.

In this present study, having a previous temporary ileostomy (sometimes more than once) seemed to ease the adjustment to the eventual permanent ileostomy. A temporary stoma seemed to serve as a trial period making adjustment to living with the permanent ileostomy less traumatic. No studies examining quality of life discussed the notion that having a temporary ileostomy facilitated later adjustment to a permanent ileostomy. This observation implies a need for further study.

Impact on Working Capacity

The young adults in the present study returned to their preoperative employment and activities. This contrasts to studies reporting 11 to 37 percent of respondents changing their employment (Awad et al. 1993; Nugent et al. 1999). One participant in the present study suffered stoma complications, which may in the future dictate a change of employment. For several participants education was ongoing and career paths were still being determined; perhaps the challenge of living with an ileostomy would influence career path choices.

Body Image

Six studies, (Awad et al. 1993; Azizah et al. 1998; Gloeckner, 1984; Kennedy, 1988; Nugent et al. 1999; Salter, 1992) found that having an ileostomy negatively impacted sexual relationships. Societal norms and taboos play a major role in sexuality

and body image issues (Santos, 1998). Six of the seven young adults in this study expressed how the ileostomy negatively affected their body image. The unmarried participants wondered about their sexual desirability and if they would ever form a meaningful relationship. The married participants worried about their spouses' responses to the ileostomy; one participant expressed surprise that her husband still considered her attractive. In contrast, sexual function improved for one married participant.

Stoma Complications

Studies showed that a high percentage (34, 39 & 57 percent) of people living with ileostomies have stoma complications (Awad et al. 1993; Kohler et al. 1991; Park et al., 1999). Peristomal skin irritation was reported by six of the seven participants in this study, which is the most common early and late complication found by Park et al. Peristomal skin irritation often is the factor contributing to appliance leakage and if not treated can lead to other skin complications. This common complication needs to be addressed so preventive and management strategies are components of postoperative teaching and lifelong learning to enhance coping in their lifestyle.

Educational Needs

The literature suggests a deficiency in preoperative and postoperative patient teaching (Borwell, 1997; Elcoat, 1988; Nugent et al. 1999; Persson & Hellstrom, 2003; Shipes, 1987). Most of the participants in the present study voiced concerns regarding the lack of information received. Also the young adults in this study had a higher need for all the available information to assist them to meet future challenges living with a

permanent ileostomy while at the same time facing the tasks of completing education, choosing career paths, and re-establishing social and family patterns. Many participants turned to resources outside of the acute care setting.

One study (Borwell, 1997) found one third or fewer stoma care nurses had recognized counseling or psychosexual education. Another study (Azizah et al. 1998) suggested that psychiatrists and psychologists best address sexuality issues. Reflecting on the studies in the literature and concerns of this studies' participants, health care providers with an advanced preparation in sexual counseling should be a member of the health care team providing care to discuss sexual concerns and help lessen the negative impact of an ileostomy on body image.

Messages for Nursing Practice

Reflecting on the participants' stories made me examine specific components of nursing practice: the art of listening, exhibiting respect and dignity, and imparting information and teaching. In addition I reflected on the role of the ET nurse advanced practice.

Active listening is an important component of nursing care. We may listen but do we hear our patients? When listening to patients at bedside conversations, nurses need to make a conscious effort to hear what is being said. I believe listening is interactive and has three components; what is being said, how it is said and why it is being said. Listening gives meaning and respect to patients' stories, conversations, past experiences and to their self. Nurses need to take the time to converse with their patients, listen, pay attention and respond to messages being given. Silence also can carry messages.

Hospital environments can be threatening for patients and some patients may be shy, reluctant or afraid to speak. Nurses need to be aware of silences, cognizant of their meaning and skillfully enable patients to voice concerns and ask questions.

Lee (1970) described four phases that can occur when a person experiences trauma resulting in an altered body appearance: (a) impact, (b) retreat, (c) acknowledgment and, (d) reconstruction. She also addressed implications for nurses in each phase. I believe these phases are relevant to the population in this study. The first phase, impact occurs when the patient fully understands what happened. Some of the participants reported that they were shocked at the first sight of their stoma. Lee wrote of the importance of nurses examining their own feelings when caring for patients experiencing trauma resulting in altered body image. Sometimes facial expressions, comments and attitudes unknowingly communicate nursing attitudes. Nurses need to recognize their own feelings and be respectful commenting about patients' situations.

The second phase, retreat, is viewed as a rest period and defensive phase in which the patient recovers from the acute phase (Lee, 1970). One participant in this study recalled wanting to be left alone and several participants remembered being pushed to learn self-care before recovering from the acute phase of their illness. During this time the patient reorganizes, strengthens, and prepares for the next steps in recovery. Lee felt it is the nurse's role to recognize what is happening with patients. This phase may require delaying teaching stoma care. What energy an ill patient has in this phase is probably channeled into coping with the physiological demands of the illness. Physical and mental readiness to learn can be extremely limited during this time (Whitman et al. 1986).

Several participants related that they did not remember the teaching of self-care from day to day.

Knowing when to teach is a crucial factor in the teaching process and careful patient assessment by ET nurses and health care providers will help determine patient readiness. Participants who had emergency surgery felt they were not ready for teaching of self-care when it was initiated. In today's health care environment of shortened stays and earlier discharge, teaching stoma care and management is a high priority and accommodating patient readiness may be a difficult task. Home care nursing support is not always required or desired; but this service should always be available to help foster patient independence.

Education is accepted as an integral part of nursing practice. In an acute care institution where ET nurses are employed, it may be assumed that teaching related to the patient's ileostomy should be left to the ET nurse. One-on-one discharge teaching of stoma care and management seemed to be sufficient for the participants in this study. However, participants desired more written information than was offered to prepare them for all possible future incidents and challenges of living with their ileostomy. I suggest every nurse has a responsibility to help educate patients regarding their ileostomy ensuring concerns and questions are addressed within an appropriate time period.

Some participants had a visitor through the United Ostomy Association (UOA) visitation program and others did not. The intent of the program is to match the visitor with the patient's gender, age, surgery, disease and marital status; however, because of the volunteer nature, an appropriate visitor may not always be available. At times it may be a judgment call, trying to arrange an appropriate visitor for a patient. Participants in

this study all recognized the value of an ostomy visitor and felt that speaking with someone in a similar situation was an important factor in adjusting living with an ileostomy. One participant felt the ostomy visitor was the most valuable component of all the teaching she received; another participant believed having two visitors confirmed his surgical decision as being right for him.

Unfortunately one participant received a visitor with whom he could not relate because they were different ages and in different life stages. I believe having an UOA visitor is an important and valuable component of patient teaching giving patients the opportunity of talking with someone with similar surgeries and situations. However it is important that visitors are matched as close as possible to the patient so meaningful conversation can take place. Several participants voiced the desire to become a member of the support group.

Lee's (1970) third phase of acknowledgment, the mourning period, also has implications for nursing practice. Patients who have ileostomy surgery usually lose a significant part of their bowel and all have a new body appearance and image. I believe many patients do not recognize experiencing a mourning period. Cassell (1991) wrote that suffering is distress experienced by patients threatened with the loss of body integrity and believed adequate nursing care cannot happen until nurses recognize the suffering. The recognition and acknowledgment of suffering related to the loss of body integrity and image enables patients to move forward in adjusting to living with their new body (Lee).

The impact of ostomy surgery in the hospital recovery period for a person can be a very difficult and emotional time. Two participants recalled crying; distressed at

loosing their colon and part of the small intestine and at the same time having a “new part”, an ileostomy. Both resisted further surgery to remove the rectum. Another participant recalled the nursing attitudes as uncaring, complacent and disgusted at his ileostomy, left him wondering how he was ever going to live with an ileostomy. Positive attitudes of health care providers and recognition of patient suffering can enable patients to begin the journey of adjusting to living with a permanent ileostomy.

Messages for Nursing Researchers

Narrative stories are an important method of gaining a comprehensive understanding of human experience. Generally nurses live in different worlds than their patients. Reflecting and understanding patients’ lifeworlds enables nurses to make sense of patients’ experiences and why they are as they are. Frank (2000) stated that people who tell stories do so to be heard and stories can assist nurses to cross the bridge into patients’ worlds and “... *see the shape of the other’s life as the other experiences it*” (Frank, p.365).

Reflecting on my past ET nurse practice and based on the number of permanent ileostomies performed by a busy colon and rectal surgeon in Calgary during the past three years, permanent ileostomies are becoming a less common surgical procedure. This does not negate, however, the importance of understanding the experiences of this patient population and their unique needs. This surgical procedure causes patients distress and requires major life adjustments. Through research, nurses have the vehicle to understand everyday situations with patients, discuss and communicate understanding with colleagues, and change nursing practice.

Some possible future directions for nursing research relating to the population living with an ostomy, listed in order of importance as I identify them, are: (a) identifying common peristomal skin complications and corresponding preventative teaching strategies, (b) identifying resources and approaches for continuing support and education in the community, (c) assessing the effectiveness of the United Ostomy Association visitation program and its impact on patients' adjustments, (d) examining beliefs and attitudes of nurses caring for patients with ostomies in acute care, (e) evaluating the effectiveness of pouch convexity for retracted stomas, (f) comparing patient adjustments to temporary ostomies compared with permanent ostomies, (g) examining the perceptions of body image changes in young female adults compared to young male adults and compare younger adults' perceptions with older adults, and, (h) examining adjustment to a permanent ileostomy as an elective versus emergency surgery.

Evidence-based practice is needed to provide a foundation to guide the nursing care of persons who have ostomy surgery. Research serves to enhance patient outcomes, improve patient and nursing education and provide a base for the continuity of patient care. Research can only strengthen the credibility of ostomy management.

Messages for Enterostomal Nursing Practice

Based on the participants' stories and my past ET nursing there is an obvious need for additional resources to help patients adjust to living with permanent ostomies. Patient acuity, ET nurse – patient ratio, the ET nurses' diverse responsibilities and early discharges are factors potentially limiting patient teaching regarding stoma care and management. I believe because of constraints on their time ET nurses' practice is limited

to the preparation for impending surgery and/or the immediate adjustment post-operatively. Nevertheless one-on-one discharge teaching of the physical stoma care and management seemed to be sufficient for the participants in this study.

In Canada diploma-prepared registered nurses (RN) are currently accepted into the distance-delivered Canadian Association for Enterostomal Therapy (CAET) education program. The CAET is an affiliate member of the Canadian Nurses Association and the process for recognizing ET nursing as a specialty and eventual certification is currently under review and development. In the United States ET nursing is a certified specialty that accepts only baccalaureate prepared nurses. If completed on site the programs are approximately eight weeks in length. The CAET program advisors in Canada are currently considering accepting only baccalaureate prepared nurses. The development of advanced ET expertise and competence often requires years of related clinical practice.

Participants expressed the need for access to all available information to help them face future challenges in living with an ileostomy. Participants also recognized the value of conversing with people who experienced similar surgery. Several suggestions for ET practice are: (a) provision of information (written and / or video) or a list, including source, of all available information to patients, (b) educating and mentoring surgical staff nurses and other health care providers, and (c) providing the opportunity for all patients to connect with an appropriate United Ostomy Association (UOA) visitor. A suggestion for the CAET is to compile a list of all available patient education material in English and other languages and distribute this to ET nurses in the CAET's directory. The list should also be placed on CAET's website and updated regularly.

Body image is an integral aspect of sexuality (Anastasia, 1998). Literature (Awad et al. 1993; Azizah et al. 1998; Gloeckner, 1984; Kennedy, 1988; Nugent et al. 1999; Salter, 1992) documents the negative impact of ostomy surgery on body image and this is supported by the findings in this study. Generally today patients exhibit an increased awareness, have more education and are more candid. Literature suggest that health care providers specializing in psychosexual adjustment best address issues surrounding body image and sexuality (Azizah et al. 1998; Borwell, 1997). The current Canadian ET distance educational program introduces the basic components of psychosexual counseling; however, the provision of education and related clinical experience for in-depth psychosexual counseling is beyond the scope of the program.

Reflecting on past practice, current education and the participant's stories I suggest that there is a need for ET nurses prepared at the advanced nursing level of practice. Direct clinical practice is central to the ET role. However, a need for advanced practice in communication, teaching and learning, counselling, and political and social marketing for change is also apparent. An ET nurse prepared at the graduate level would incorporate the clinical expertise of the ET education program with the skills of an advanced practice nurse, including psychosexual counseling.

A move towards community-based treatment is apparent. An ET nurse, prepared at the advanced practice level possesses the skills and knowledge to expand the role to incorporate community practice. Following discharge, living with an ostomy becomes a reality and adjustment issues may need to be addressed. I believe ET advanced practice nurses require flexibility within their roles to allow for the community care that can be offered by case management. The delivery of health care is changing. An ET nurse

prepared at the advanced practice level has the clinical and professional leadership skills required for role development and change as delivery of health care and patients' needs evolve.

Thoughts on the Method

I conclude with some personal reflections on the interview process, writing the report and dissemination of the findings.

Interview Process

The interviews were informal and unstructured. Conducting an interview for a qualitative narrative study is very different from obtaining histories and the verbal interactions in the every day nursing practice in an acute care setting. At times I was reluctant to ask a question or make a comment, thinking this would interrupt the flow of the participants' narrative. Interviewing is a skill and I believe it takes practice. During the first interview I made field notes with the intent of asking my questions at the conclusion of the interview. This was effective in obtaining more data but I learned with the succeeding interviews to ask questions at the appropriate time of the interview, which seemed more effective and connected to the flow of the story. I learned each interviewee and interview was unique and I had to adjust my approach according.

The unstructured informal format provided no boundaries for the participants, providing them the freedom to speak as they wished. The interview guidelines presented and explained to participants suggested a one-hour interview or longer depending on the

conversation flow. One hour proved too short for all participants except one, interviews stretched beyond the hour and one participant spoke for more than two hours.

Later in transcribing and reading the transcriptions I formed more questions and realized the potential value of a following second interview. The rapid flow of conversations tended to bury questions that became apparent when later reading the transcriptions. A second interview would have helped clarify some points; however, follow-up interviews were beyond the scope of this study. Despite these reflections post study, rich data were obtained from the participants' stories.

Writing the Report

"Voice and signature are closely connected in the writing and transforming of field texts into research texts" (Clandinin & Connelly, 2000, p.147). A challenge exists in narrative inquiry creating research text and expressing one's own voice while representing the voices of the participants' storied experiences. The reconstructed stories of the participants were written in their own words thus remaining faithful to their voices. Personal biases or too much voice are at risk for emerging in the text of narrative research. I found it a challenge to reveal the participants' unique stories while trying to condense the field texts into the research texts. I returned numerous times to the interviews ensuring I was remaining true to their voices and not obscuring or silencing important parts. I also revisited the reconstructed stories several times attempting to shorten them without losing relevant content.

Signature refers to the researcher's writing style or their "stamp" on their work (Clandinin & Connelly, 2000). Signature belongs to both the researcher and the

participant. The participant has to recognize his or her own story. If the researcher's signature is too vivid, a risk of concealing participants' stories exists and conversely if signature is too soft the research text may reflect only participants' standpoint. The aim of the study was to portray the stories of young adults living with permanent ileostomies and to identify common themes across the stories. Therefore I allowed the participants' signature to be foremost so readers could form their own interpretation of the stories.

Dissemination of the Findings

The report of the findings must be shortened considerably as journals have limited space. In doing so, I must remain true to the participants' stories and recognize the subjective process of reducing their stories. It was a challenge deciding what to omit and what to include. The report needs to be clinically significant and plausible for intended audiences and written in a manner ensuring an impact in the delivery of care for people who have ileostomies. I believe the findings speak to people of all age groups who have ostomy surgery.

There is a need to present the findings to all health care providers; however, the ET community and surgical nurses are specific targets. I see a global message for all health care providers to avoid the possibility of becoming complacent and methodical in the delivery of care to people who have ostomy surgery and for all patients experiencing an altered body appearance. Recognition, understanding and respect of each person's unique journey through the process of ostomy surgery are important in helping people adjust to living with an ileostomy.

Summary

The impetus for this study was my past ET nursing practice and my wish to understand more fully the experiences of young adults living with permanent ileostomies. I perceived patients were not completely forthcoming during clinic visits post-discharge but rather gave restricted information based on what they thought was of clinical interest. I suggested this to a participant following his interview, he laughed and replied, "*You're pretty much right.*"

This study opened a new door for me. I felt privileged that individuals agreed to participate, allowing me to listen to their stories and receiving information not shared previously. I was appalled listening to two participants recalling their experiences of mismanaged pain post-operatively. I believed that post-operative pain was well managed and given high priority. I was not completely surprised by participants' experiencing negative nursing attitudes. Unfortunately negative experiences appear to have a profound impact of long duration. Although some participants received excellent care, I believe those participants recalling negative experiences were still suffering from the impact.

A second interview would have been valuable in gaining a fuller understanding of the participants' lives as sometimes the rapid conversational flow of the interview did not always allow for probing and drawing out in-depth information. Returning to the transcripts and stories numerous times left me wondering what information was left uncovered. However, this study allowed me a glimpse into the lives of the participants living with permanent ileostomies. Several participants remarked that no one could truly understand living with an ileostomy unless you have one. I hear, respect what I have

been told, and acknowledge as an outsider that I could not really enter their worlds.

However I have gained greater insight and understanding of their lives.

Atkinson (1998) stated that we are each other's teachers; the person sharing his or her life story is the teacher and the person receiving the story is the student. I know over my many years as a practicing ET nurse, I valued my patients as teachers. Van Manen (1997) believed that reflection on practice results in understanding and in turn enlightens practice. Reflecting on my past practice I feel confident that today my ET nursing practice would be different. I would like to thank the participants for sharing their stories and enriching my understanding of living with a permanent ileostomy.

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APPENDIX A

ETHICAL APPROVAL

FROM

THE CONJOINT HEALTH RESEARCH ETHICS BOARD



FACULTY OF MEDICINE

Office of Medical Bioethics
Heritage Medical Research Building/Rm 93
Telephone: (403) 220-7990
Fax: (403) 283-8524

2003-03-11

Dr. D. Hughes
Faculty of Nursing, PF 2210
University of Calgary
Calgary, Alberta

Dear Dr. Hughes:

RE: Stories of Young Adults with Permanent Ileostomies
Student: Ms. Lorraine Sinclair Degree: MN

Grant-ID: 16987

The above-noted thesis proposal and the consent form have been submitted for Committee review and found to be ethically acceptable. Please note that this approval is subject to the following conditions:

- (1) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (2) a Progress Report must be submitted by 2004-03-11, containing the following information:
 - (i) the number of subjects recruited;
 - (ii) a description of any protocol modification;
 - (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
 - (v) a copy of the current informed consent form;
 - (vi) the expected date of termination of this project;
- (3) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC
Chair, Conjoint Health Research Ethics Board

cc: Adult Research Committee

Dr. M. Reimer (information)

Research Services

Ms. Lorraine Sinclair



calgary health region
Foothills Medical Centre

12 March 2003

Dr. Dorothy Hughes
Faculty of Nursing
University of Calgary

Dear Dr. Hughes:

Re: #16987 - Stories of Young Adults with Permanent Ileostomies

Thank you for submitting an application regarding the above project for review by the Adult Research Committee of the Calgary Health Region (CHR). This will confirm that the committee has granted institutional approval for this project, **contingent on approval by the Conjoint Health Research Ethics Board.**

It is understood from your submission that your study will be entirely funded through external sources and that the CHR will be reimbursed for all research costs associated with this project if applicable. To facilitate a smooth startup of your project, please notify affected departments in the Region well in advance of your intent to initiate this study.

Please note that it is a requirement that you communicate in writing the study results to the CHR Adult Research Committee, and provide any copies of publications arising from the research as well as provide feedback regarding any problems encountered during the course of the study.

Please accept the committee's best wishes for success in your research.

Yours sincerely,

John Jarrell, MD
Interim Chair, Adult Research Committee

cc: Dr. M Reimer, Ms. L Sinclair, Conjoint Health Research Ethics Board

APPENDIX B

CONSENT FORM



FACULTY OF NURSING

Telephone: (403) 220-4650

Fax: (403) 284-4803

Email: hughes@ucalgary.ca

CONSENT FORM

TITLE: Stories of Young Adults with Permanent Ileostomies

SPONSOR: Faculty of Nursing, University of Calgary

INVESTIGATORS: Principal Investigator: Dr. D. Hughes
Associate Professor, Faculty of Nursing

Co-investigator: Lorraine Sinclair
MN student, University of Calgary

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND:

The purpose of this study is to help nurses understand what it is like for young adults to live with permanent ileostomies. The knowledge will help ET nurses give better care to patients similar to you.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to gain an in-depth understanding of what it is like for young adults to live with a permanent ileostomy.

WHAT WOULD I HAVE TO DO?

If you agree to take part in this study you will meet with Lorraine Sinclair for about 1 to 1 ½ hours. Lorraine will ask you to tell your story about living with an ileostomy. Your conversation will be tape recorded, and later Lorraine Sinclair will transcribe it (type it out). The interview will take place wherever you prefer and at a time that is convenient for both of you. Lorraine may take additional hand written notes during the interview and the audiotaping.

She might also ask you to review your interview transcript to be sure that it is right. If you wish, a copy of the research report will be sent to you once it is finished.

WHAT ARE THE RISKS?

There are no known risks to you by participating in the study. It is possible that by talking of some of your experiences with living with an ostomy may upset you. If you so desire, you may ask for the interview to be stopped. If this has been upsetting to you, Lorraine (an experienced enterostomal therapy nurse) will stay with you and discuss it if you like, and will encourage you to visit your surgeon and / or family physician to speak with them about your concerns. If necessary, you may be referred to a counseling psychologist, but the investigators will not cover the expenses.

WILL I BENEFIT IF I TAKE PART?

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If you agree to participate in this study there may or may not be a direct benefit to you. You might find it helpful to discuss your experiences but there is no guarantee that this research will help you. The information we get from this study may help us to provide better treatments in the future for patients with permanent ileostomies.

DO I HAVE TO PARTICIPATE?

Your participation is entirely voluntary. You may choose not to participate or to withdraw from the study at any time without affecting future health care. You may withdraw by informing the principal investigator or the co-investigator / interviewer. If you choose to withdraw, your interview tape will be destroyed.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Participation in the study will involve no cost to you. If you have to pay for parking we will pay you back. You will not be paid for taking part in the study. There is no funding agency or funding body involved in this study.

WILL MY RECORDS BE KEPT PRIVATE?

The audiotapes will be transcribed by Lorraine Sinclair or by a paid medical transcriber who will not be able to identify you by name. During the study the tapes will be kept in a locked drawer by the co-investigator and will be erased at the completion of the study. Only the principal investigator and the co-investigator will have access to the tapes. The transcriptions will be retained for up to five years following the study for possible further analysis. The University of Calgary Conjoint Research Ethics Board will have access to the records. Information and quotes obtained in this study may be published in health care journals, but your identity will not be revealed.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. D. Hughes (403) 220 4650

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C

LETTER FROM DR. BUIE

W. DONALD BUIE, M.D., M.Sc., F.R.C.S.C., F.A.C.S.*

Colon and Rectal Surgery - General Surgery

131

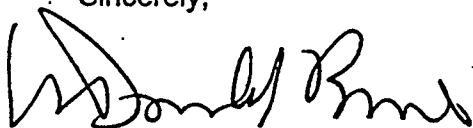
*Foothills Hospital
1403 - 29th St. N.W.
Calgary, AB T2N 2T9
Bus. (403) 944-2020
Fax (403) 270-8004*

February 6, 2003

To Whom It May Concern:

This letter acknowledges that I support Lorraine Sinclair's qualitative research thesis titled *The Stories of Young Adults with Permanent Ileostomies*. Interested participants will be recruited from my clinical practice. Patients who meet the specified criteria will be approached by myself or by my clinic nurse, Trish Landry. Interested patients will be given Lorraine's letter of introduction and instructed to contact her directly or give us permission to inform Lorraine of their interest and give her their contact phone number.

Sincerely,



W. Donald Buie, MD, MSc, FRCSC, FACS
WDB/bj

APPENDIX D

LETTER OF INTRODUCTION



Hello,

My name is Lorraine Sinclair. I am an enterostomal therapy nurse and currently enrolled as a master's student in the Faculty of Nursing at the University of Calgary. For my thesis I am interested in hearing stories of young adults who live with a permanent ileostomy.

The purpose of the study is to gain an understanding of what it is like to live with a permanent ileostomy from your perspective. Your participation will involve one interview that will be audio taped and last approximately, but not limited to 60 to 90 minutes. Depending upon how you feel the interview can be longer than 90 minutes. The place of the interview will be your choice and at a mutually convenient time. The ultimate purpose of this study is to contribute knowledge that can be used by ET nurses and nurses in general in providing improved care to people who may be anticipating having ostomy surgery or who live with an ostomy. The information you provide will be treated with the utmost confidentiality. Your name will be changed in the final report and all material that may have the potential of identifying you will be excluded.

If you are interested in participating in this study you are invited to contact me at the phone number below or give Dr. Buie or his clinic nurse (Trish) permission for me to contact you. Thank-you.

Sincerely,

Lorraine Sinclair, RN, BN, ET
MN student, University of Calgary
Phone # 403 241 1110