

Living with Inflammatory Bowel Disease (IBD) and an Ostomy: An Integrative Review

Catherine Colman, RN, BScN, University of Victoria

A Project Submitted in Partial Fulfillment of the Requirements for the Degree of

Master's in Nursing in the School of Nursing, University of Victoria

Faculty of Human and Social Development

August 25th, 2014

Supervisor: Elizabeth Banister, PhD, RN, R Psych, Professor, School of Nursing

Project Committee Member: Rosalie Starzomski, PhD, RN, Professor, School of Nursing

Abstract

A paramount concern for patients living with inflammatory bowel disease (IBD) is having to undergo surgery resulting in an ostomy. Adaptation is unique to the individual, and an IBD patient may face adaptation challenges that are different from those with other medical conditions. To develop a comprehensive understanding of the adaptation process of those living with IBD and an ostomy, and to identify ways in which advanced practice nurses can best support and foster positive adaptation, an integrative review of the current literature related to living with IBD and an ostomy was performed. Roy's adaptation model provided the theoretical foundation and helped to inform this review. A total of 14 articles (seven quantitative and seven qualitative) met the inclusion criteria. Key findings of this review are: *experiences of shame*, which is associated with body dissatisfaction, alterations in sexuality and fears of rejection; *the need for social-connectedness* and value of empathic support; and finally, the experience of grief and loss and *resolve to live again*. This integrative review has contributed to existing knowledge and has informed advanced practice nursing by illuminating a greater awareness of the struggles and triumphs that ostomized IBD patients face. Findings from this review also capture and validate the usefulness of Roy's adaptation model in nursing research. Implications for nursing practice and recommendations for future research are offered.

Keywords: adaptation, ostomy, inflammatory bowel disease (IBD), nursing

Table of Contents

Chapter I: My Area of Interest.....	6
Background	7
Statement of the Problem/Phenomena	11
Purpose of the Proposed Project.....	12
Project Objectives	12
Chapter II: Approach to the Inquiry.....	13
Methodology	13
Inclusion and Exclusion Criteria.....	13
Theoretical Approach – Roy’s Adaptation Model	15
Goals and the four adaptive modes of the adaptation model.....	16
The physiologic-physical mode	16
The self-concept mode	17
The interdependence mode	17
The role function mode	17
Relational Ethics	19
Description of the Qualitative and Quantitative Frameworks.....	20
Qualitative framework.....	20
Quantitative framework.....	21
Chapter III: Findings.....	22
Experiences of Shame	22
Body image.....	23
Sexuality	25
Fear of rejection.....	26
The Need for Social Connectedness.....	28

Support system	29
Value of peer connections	30
Significant others	32
The Resolve to Live Again.....	34
Shock and disbelief.....	35
Apprehending or taking hold of the loss	36
Attempting to deal with the loss	36
Final restitution and resolution	37
Chapter IV: Discussion	39
Summary of the Findings	39
Experiences of shame	39
The need for social connectedness	39
The resolve to live again.....	40
Summary of the Methodology.....	40
Summary of the Theoretical Model(s)	41
Roy's adaptation model	41
Relational ethics	41
Implications for Practice	42
Implications for advance practice.....	42
Sexuality and body image	42
Social functioning	44
Nursing ethics	45
Implications for nursing education	46
Self-care promotion.....	46
Information seeking	47

Utilizing assessment tools in practice	47
Advancement of staff nurse education.....	48
Recommendations for Future Research	48
Limitations	49
Conclusion.....	50
References.....	52
Appendix A: Qualitative Evidence Review Framework	59
Appendix B: Quantitative Evidence Review Framework.....	61
Appendix C: Summary of Qualitative Research Articles	63
Appendix D: Summary of Quantitative Research Articles.....	70

Chapter 1: My Area of Interest

“I’d rather die than live my life with a bag” (Anon 1, 2013)

“I’m so sick of being sick; I’ll be alright with the bag” (Anon 2, 2013)

Caring for patients and families living with a chronic health condition comes with a host of challenges. These challenges can stem from the symptomatology of the disease process to the psychosocial burden of living with a chronic disease. As a nurse working with those living with inflammatory bowel disease (IBD), the significance of IBD on patients’ day to day living and quality of life (QOL) cannot be overstated. The impact is evident throughout all areas of life, from the burden of debilitating symptoms such as abdominal pain, persistent diarrhea, anorexia, fatigue and rectal bleeding; to the inability to attend school or go to work; to the psychological impact associated with stress, depression, social stigma and social isolation; and to difficulties with physical intimacy (CCFC, 2012).

Most people with IBD require an individualized therapeutic regime; however, when the disease becomes medically unmanageable or when complications arise, surgery is often required (CCFC, 2012). The decision to undergo colorectal surgery can be difficult for patients and families. This is especially true when faced with the prospect that surgery may result in the formation of an often irreversible ostomy, where waste is diverted into a collection pouch fastened to the abdomen. Patients may delay or refuse a potentially life-saving procedure even with the understanding that the choice could be life threatening. In my practice, some patients have shared that they would rather die than live with a bag. In contrast, other patients desire the surgery in hopes that their suffering will be relieved. My understanding from clinical experience including discussion with colleagues is that certain factors seem to influence patients’ choices in favour of surgery. Factors suggested from clinical practice include, but are not limited to: long-standing disease duration, disease severity, steroid dependency, fear of colon cancer and a

supportive relationship. For those who may be less accepting of surgery, factors include shorter disease duration, young adult population (18-30), lack of social support and fear of post-surgery disease recurrence.

What do we know about adaptation to life with an ostomy for those living with IBD? To assist in my own comprehension of the complexities surrounding IBD patients' adaptation while living with an ostomy, I will draw upon my own clinical experiences as an IBD nurse and will reflect upon those experiences shared by my colleagues. Reviewing some of the published research literature will also assist in broadening my understanding. In order to gain greater insight into those living with IBD and an ostomy, I shall examine and synthesize through the methodological process of an integrative literature review selected qualitative and quantitative research studies that meet my inclusion and exclusion criteria.

Background

Inflammatory Bowel Disease (IBD) is a chronic inflammatory gastrointestinal disease comprised of two similar yet distinct subgroups, Crohn's disease and ulcerative colitis. IBD affects approximately 233,000 Canadians: 129,000 with Crohn's disease and 104,000 with ulcerative colitis (CCFC, 2012). Canada has the highest reported prevalence of IBD in the world (CCFC, 2012). The specific cause of IBD has not yet been established; however there is growing evidence to suggest that a combination of environmental and genetic factors play a role "in inappropriately activating the gastrointestinal immune system" (CCFC, 2012 p. 27). IBD is characterized by periods of increased symptom acuity and disease activity, followed by a quietened remissive state (Bayless & Hanauer, 2001). It is commonly first diagnosed in early adulthood, but may occur at any age (Boye et al, 2011; CCFC, 2012). Patients may present with

symptoms ranging from mild to moderate gastrointestinal disturbances to severe, debilitating and sometimes life threatening complications (CCFC, 2012; Saibil, 2011).

The main difference between Crohn's disease and ulcerative colitis is that Crohn's disease can present anywhere along the gastrointestinal tract from the mouth to the anus, whereas ulcerative colitis is confined to the rectum and large intestine (Saibil, Hayward & Gilbert 2008; Schneider & Fletcher, 2008). Crohn's disease and ulcerative colitis share many of the same symptoms; but, given the varying location of Crohn's disease, and the fact that Crohn's disease penetrates more deeply into the bowel lining, means that abdominal pain may be more of a consistent feature (Steinhart, 2006). Extra-intestinal manifestations, which can affect the eyes, skin, bones, joints and liver are prominent, and complications such as fistulas, abscesses, and intestinal obstructions place Crohn's disease patients at an increased risk for surgery (CCFC, 2012; Saibil, 2011; Steinhart, 2006). In fact, approximately two thirds to three quarters of people with Crohn's disease, and approximately one quarter to one third with ulcerative colitis, will undergo surgery at some point during the course of their disease (CCFC, 2012). There is no medical or surgical cure for Crohn's disease; for ulcerative colitis the only curative solution is a colectomy, the removal of the large intestine (Bayless & Hanauer, 2001; Schneider & Fletcher, 2008).

Patients with ulcerative colitis requiring surgery may undergo two types of procedures: a colectomy with an ileostomy or an ileal pouch-anal anastomosis (IPAA) (Steinhart, 2006). With an ileostomy, the end of the small intestine (ileum) is brought out through the surface of the abdomen. Stool then exits the body through the "stoma" or opening, into an external appliance or ostomy bag (CCFC, 2012; Saibil, 2011). For an ileal pouch-anal anastomosis, a surgically made reservoir or "pouch" is made from the ileum. The pouch which substitutes for the rectum, is

created by folding the ileum back on itself and is then attached to the anal sphincter muscle by which the patient can then evacuate naturally (Saibil, 2011; Steinhart, 2006). An ileal pouch-anal anastomosis is usually done in two or three stages where the patient lives with a temporary ileostomy for approximately three to six months or until the area has healed, and the ostomy can be closed (Steinhart, 2006). This procedure is not usually offered to patients with Crohn's disease due to the high probability of complications such as perineal sepsis, disease recurrence and poor pouch function (Saibil, 2011; Steinhart). As per Perry-Woodford (2013), ileo-anal pouch failure occurs in up to 20% of patients and requires additional surgery resulting in a permanent ileostomy (as cited in Lepistö, Luukkonen & Järvinen, 2002).

As mentioned, Crohn's disease can present anywhere along the gastrointestinal tract (Saibil, Hayward & Gilbert 2008; Schneider & Fletcher, 2008). Therefore, surgery for Crohn's disease depends on location as well as the severity of disease. A common location for most people with Crohn's disease is the last part of the small intestine (Saibil, 2011). Consequently, the most common surgery performed is a small intestinal resection (Steinhart, 2006). During this procedure, the diseased segment of bowel is removed and two ends of healthy intestine are joined together in a technique called an anastomosis (CCFC, 2012). A temporary ostomy may be required in some instances such as with uncontrolled infection related to an abscess, or to divert away from a repaired fistula (Saibil, 2011; Steinhart, 2006). Due the nature of Crohn's disease, recurrence can occur at the site of the anastomosis and require further surgeries (CCFC, 2012). When there is no healthy bowel to connect to, an ostomy may be required (CCFC, 2012). Up to 10% of persons with Crohn's disease will require either a temporary or permanent ostomy at some point along the trajectory of their disease (Brown & Randle, 2004).

One of the greatest worries for a patient living with inflammatory bowel disease (IBD) is to undergo surgery with the outcome of living life with an ostomy (Canavan, Abrams, Hawthorne, Drossman & Mayberry, 2006; Drossman, 1989; Levinstein et al. 2001). IBD patients and their families face a variety of concerns as they navigate towards this life altering decision. Researchers indicate that those who undergo colorectal surgery resulting in an ostomy experience social and psychological issues, such as low self-esteem, social isolation, stigma, poor adaptation, sexual impairment, depression and suicidal thoughts (Richbourg, Thorpe, Rapp, 2007; Simmons, Smith, Bobb, & Liles, 2007). In contrast, according to Junkin and Beitz (2005) and O'Brien (1999), many patients look forward to the surgery with the hopes of a positive outcome of improved health and the possibility of a normal lifestyle (as cited in Savard & Woodgate, 2009). My clinical experience supports these findings. For example, one patient shared that managing this new life with an ostomy can sometimes be a struggle. For this patient, the feeling of being "different" was at times lonely and isolating. In contrast, another patient shared feelings of being "reborn", finally free of pain, and eagerly awaiting to start up life again.

According to Roy (2008), positive adaptation contributes to health and quality of life (QOL). The ability to positively cope with a changing environment is reflective of how one effectively or ineffectively adapts (Roy, 2008). A number of IBD researchers suggest that patients report healthy adaptation and a (QOL) better or similar to the general population following ostomy formation (Camilleri-Brennan Steele, 2001; McLeod & Baxter, 1998). Other researchers, however, indicate that adaptation and QOL post ostomy creation is poor (Knowles et al., 2013; Notter & Burnard, 2006). Generally, studies have been performed in order to measure QOL, most using structured questionnaires that were not focussed exclusively on IBD, but included other medical conditions such as colon and rectal cancers, trauma, diverticulitis, and

infection (Silva, Ratnayake & Deen, 2003; Sjö Dahl, Schulz, Myrelid & Andersson, 2012).

Studies on the lives of stoma patients have also been performed; findings include: altered body image, sexual dysfunction and psychosocial maladjustment (Brown & Randle, 2005; Danielsen, 2013).

To date, there are a limited number of studies capturing the subjective experience of IBD patients living with an ostomy (Frohlich, 2012; Savard & Woodgate, 2009; Sinclair, 2009).

There is, however, an abundance of research not specific to IBD that confirms the impact on life and the challenges of physically and psychosocially adapting, and the loss of embodied wholeness that comes with ostomy and stoma placement (Honkala & Bertero, 2009; Danielsen, Soerensen, Burcharth & Rosenberg, 2012; Thorpe & Richardson 2009). Considering the lack of consistency in the literature surrounding IBD patients' experience of living with an ostomy, an integrative review of selected literature can shed light on this complex healthcare issue. By identifying adaptation factors that are characteristic to the IBD population, a greater understanding of the physical and psychosocial process of adaptation to life with an ostomy can advance nursing knowledge and improve practice.

Statement of the Problem/Phenomena

How can advanced practice nurses best support IBD patients through the trajectory of living with IBD and living with IBD and an ostomy? A more comprehensive understanding of those who are living with IBD and an ostomy could help to inform advanced practice nurses by exploring the strengths and challenges in adaptation that IBD patients face. The complex nature of IBD and the issues affecting these patients prompted me to explore and review selected published qualitative and quantitative research literature related to living with IBD and an ostomy. My intent with this integrative review is to add to the body of nursing knowledge so

that optimal care, improved health outcomes and greater physical and psychosocial adaptation can ensue for all ostomized IBD patients.

Purpose of the Project

My purpose in this integrative review is to examine current literature related to the adaptation process of those living with IBD and an ostomy. It is my hope that my review of the research can contribute to existing knowledge and inform advanced practice nurses by bringing to the forefront a greater awareness of the challenges and struggles with adaptation that IBD patients face.

Project Objectives

- 1) Analyze literature related to living with IBD and an ostomy.
- 2) Obtain a greater understanding of the issues faced by those living with IBD and an ostomy.
- 3) Determine ways in which advanced practice nurses can best support and foster positive adaptation in IBD patients living with an ostomy.

Chapter 2: Approach to the Inquiry

Methodology

The integrative literature review was the chosen methodology for this project. In an integrative literature review, the researcher engages in the process of reviewing critiquing, and synthesizing information on a specific topic in order to generate new knowledge (Torraco, 2005). In an integrative review, the researcher reviews and summarizes theoretical and past empirical literature while combining diverse methodologies (Whittemore & Knafl, 2005). This type of methodology allows for the inclusion of both experimental and non-experimental design so to achieve a comprehensive understanding of the phenomena under review. The various perspectives of a phenomenon of interest are important in advancing nursing science and play a great role in evidence based practice (Whittemore & Knafl, 2005). I chose the integrative review as the methodology in order to develop a comprehensive understanding of the experiences of those living with IBD and an ostomy. Whittemore and Knafl's five stages of an integrative review was followed, which included problem identification, literature search, data evaluation, data analysis, and presentation.

Inclusion and Exclusion Criteria

As mentioned, there are numerous studies that combine different conditions for which an ostomy would be indicated. For example, many researchers conducting quality of life studies combine both colon cancer and IBD, however, life experiences can be very different in these populations. For the purpose of this project, findings from literature that merge IBD with other medical concerns was not included.

The peak onset of IBD is between the ages of 15-35 (CCFC, 2012). However, for the purpose of this project, only adult populations (18 and over) were included. The literature

selected was comprised of both qualitative and quantitative research articles. All articles were written in English and were published in scholarly peer reviewed journals. Opinion and review articles, as well as unpublished manuscripts were excluded.

On December 4th 2013, a preliminary in-depth search of the literature was done. Ovid MEDLINE, Embase, PsycINFO and Cumulative Index of Nursing and Allied Health Literature (CINAHL Complete) were the databases searched. The search terms used were: experience, psychosocial, adaptation, quality of life (QOL) and living with a colostomy, stoma, ostomy or ileostomy. The population of interest was captured as Inflammatory Bowel Disease (IBD), Crohn's disease and ulcerative colitis. No date parameters were set and a total of 300 articles were found. This search strategy resulted in a significant number of articles that did not pertain to the research question under study.

After redefining key search words and applying appropriate truncations, an additional comprehensive search of the literature was completed January 7th, 2014 through the University of Victoria's on line database. The search technique EBSCOhost was used to search both CINAHL and PsycINFO using the search terms patient satisfaction or image or attitude or quality of life or coping or psychosocial or experience or adaptation AND ulcerative colitis or Crohn's disease or IBD or inflammatory bowel disease AND ostomy or colostomy or stoma or ileostomy or ileoanal. There were no date parameters set and a total of 112 hits from 1968 to 2013 were obtained. To remain current, I limited my search from year 2000 to present, this resulted in a total of 63 hits. MEDLINE using EBSCOhost was searched, using the same parameters, and 737 hits dated from 1957 to 2014 were received. Upon further review of the MEDLINE search, it was found that the majority of these articles went beyond the relevance of my investigation. I capped the search from year 2000 and limited the search words to include

inflammatory bowel disease AND ostomy and a total of 58 articles were obtained. The outcome of the database search resulted in a total of 121 articles that required further examination. After reviewing each abstract, deleting duplicate articles and filtering for those that pertain specifically to the adult population with IBD and an ostomy, a total of 12 articles were found to be appropriate for review. An ancestry search of the reference lists of retrieved articles was performed, and an additional two studies were found to be appropriate for inclusion, bringing the final count to 14 articles (Whittemore & Knafl, 2005).

Theoretical Approach: Roy's Adaptation Model (RAM)

A theoretical approach to nursing research provides a foundation for the phenomenon of scholarly work under study and offers structure and direction to the research (Lefaiver, Keough, Letizia & Lanuza, 2007). Roy's adaptation model (RAM) was used to help inform this integrative review on living with IBD and living with an ostomy. Roy's model has been used to inform IBD research focusing on adolescent and young adult population populations (Brydolf & Segesten, 1996; Decker, 2000). This model appears to be effective in terms of identifying areas of poor physiological adaptation (Brydolf & Segesten, 1996). It also has been used by researchers in identifying and selecting interventions that promote positive adaptation for adolescents with chronic conditions, such as IBD (Decker, 2000).

According to Roy (2008), adaptation is a complex process that involves a purposeful and cohesive integration of both the person and environment. Under Roy's adaptation model people are described as "holistic" biopsychosocial beings that are greater than the sum of their parts. People are capable of adapting to the three classes of stimuli, which form the environment. These include focal, contextual and residual stimuli. *Focal stimuli* are stimuli that are at the forefront of consciousness that may be internal or external. An example of a focal stimulus for an IBD

patient with an ostomy could be the ostomy itself. *Contextual stimuli* are stimuli that contribute to the effect of the focal stimuli and how one adapts or responds to the focal stimulus. A female IBD patient with an ostomy may feel embarrassed or less sexually attractive; this can further influence her to feel negative about the ostomy, hindering upon adaptation. Finally, *residual stimuli* are environmental factors that are within or outside the human system (Roy, 2008). The influence of residual stimuli is not always evident or clear to the observer (Roy, 2008). An example of a residual stimulus could be a female partner's lack of support that may contribute to her difficulty with adapting to the ostomy. When individuals interact with the environment, their response is either adaptive or ineffective; how people react may impact one or all of the following four adaptive modes: physiological-physical, self-concept–group identity, role function, and interdependence (Roy, 2008).

Understanding the psychosocial impact and the physical effect of a compromised body is important for clinicians working with those living with IBD and an ostomy. A change in the internal and/or external stimuli places stress on coping capacities (Roy, 2008). If the human adaptive system is ineffective, the stimuli that is influencing the behaviour needs to be identified (Roy, 2008). Assessing both behaviour and stimuli, and the influence that these have on the four adaptive modes, is integral to the promotion of positive adaptation in the IBD population.

Goals and the four adaptive modes of the adaptation model.

The goal of nursing as described by Roy is to promote the health of individuals and society and to foster adaptation in the four adaptive modes (Roy, 2008).

The physiologic-physical mode

The physiologic-physical mode focuses on the maintenance of basic human physiological requirements and is comprised of the following five basic needs: oxygenation, elimination,

nutrition, activity and rest, protection; and four complex processes: fluid and electrolyte and acid base balance, neurological and endocrine function. Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Alligood & Tomey, 2010).

The self-concept mode

The self-concept mode refers to the psychological and spiritual components of a person. Self-concept is defined by Roy by two subareas: the physical self and the personal self. The person's physical self is associated with body image and bodily sensations; whereas one's personal self emphasizes self-ideal, self-consistency and one's moral-ethical spiritual nature (Alligood & Tomey, 2010; Roy, 2008). The personal self is multidimensional and is influenced by the perceptions and feedback of others (Roy, 2008). Self-concept is central to each individual; meeting the needs of the physical and personal self are vital to positive adaptation and to the integrity of the other adaptive modes (Roy, 2008).

The interdependence mode

The interdependence mode refers to the value of close relationships, the ability to give and receive respect, value and love. It involves effective communication and having an adequate social support system (Roy, 2008). Satisfying personal relationships with others encourages a sense of security and promotes relational integrity (Roy, 2008). Those who achieve adaptive interdependence have learned to live successfully through the reciprocal nature of giving and receiving to significant others as well as with support systems (Roy, 2008).

The role function mode

Finally, role function focuses on social integrity, which involves knowing who one is in relation to others and how individuals' interact within society (Roy, 2008). Primary, secondary

and tertiary role development is an ongoing process throughout life; how effectively one transitions towards these role changes defines adaptation. Social adaptation is equally as important as physiological and psychological-spiritual adaptation (Roy, 2008). The four modes described are interrelated in such a way that how one acts in response to any of the adaptive modes may have an effect on any or all of the other modes (Roy, 2008).

Roy posits that optimal health and well-being is a process and a state of being contingent upon how we positively integrate, interact and adapt within our changing internal and external, social and physical environment (Roy, 2008). Of importance is that people never act in isolation but are influenced by the environment and the interaction between people and their world; this in turn affects the environment (Roy, 2008). The environment is in constant flux and people have the ability to respond, develop and grow adaptively to these changes (Roy, 2008). Although patients may not always return to a previous state of health, the way that a person is able to positively cope and respond to change can bring about improved health, increased peace and overall adaptation. The objective in achieving adaptation, health and quality of life is being and becoming an integrated and whole person (Roy, 2008).

Roy's Adaptation Model was chosen as a theoretical lens to inform this integrative review as I believe that this holistic model links positively to both the IBD patient population and to my own clinical practice. Caring for patients and families with IBD requires more than focussing in on the objective symptomatology and underlying disease process. The promotion of positive adaptation requires a collaborative and inclusive biopsychosocial approach, which takes into consideration that wellness and health are influenced not only by biological factors but sociocultural and psychological factors as well (Engel, 1977).

Life with a chronic illness such as IBD is an ever evolving and ongoing process where positive adaptation is directly related to the integrity of the entire human system in becoming integrated and whole (Roy, 2008). According to Roy, the goal of nursing is to promote adaptation in each of the four modes described. Positive adaptation requires an environment of relational integrity, engagement and trust, while keeping in the forefront of thought that people never act in isolation but are influenced by both the social and physical environments (Roy, 2008). People find meaning and a sense of security in mutual relationships. The relational concepts of environment, mutual respect, trust and engagement underpin the principles of relational ethics (Bergum, 2013). What is relational ethics and how is it associated with nursing practice and positive adaptation?

Relational Ethics

Relational ethics encompasses the traditional aspects of bioethics such as moral reasoning, but highlights relationships as the basis of ethical action (Austin, 2006). Relational ethics involves bringing together human compassion and scientific knowledge; it involves mutual respect and the importance of valuing ones differences; it also involves trust and relational engagement where personal connection and shared moments give way to seeing and interpreting situations together (Bergum, 2013).

The importance of relational ethics to nursing practice and relationship development cannot be overstated. As healthcare professionals, we have an ethical responsibility to be open, transparent and collaborative in care and to provide relevant, accurate and open information so that patients and families are adequately prepared to make an informed decision regarding their health and well-being (CNA, 2008). A trustworthy relationship is the foundation of meaningful communication; and understanding patients' needs and concerns is contingent upon this relationship (CNA, 2008). As IBD patients and families traverse towards the decision to undergo

surgery and ostomy formation, and for those who are currently living with and working towards adaptation to living with an ostomy, relational ethics plays an important role in clinical care. The concepts of environment, mutual respect, trust and engagement are salient principles of relational ethics (Bergum, 2013). These relational concepts align with the ideas surrounding Roy's adaptation model. The feeling of security that comes from acceptance, protection and a nurturing connection enhances the relational integrity of a relationship while strengthening the adaptive process (Roy, 2008). As per Roy (1990), adaptation requires motivation, action and positivity (as cited by Hanna, 2012). A catalyst towards positive adaptation can begin with a relational therapeutic environment where active listening and genuine engagement preside. Roy's adaptation model, coupled with a relational ethics lens, helped to inform my enquiry into adaptation to IBD and an ostomy.

Description of the Qualitative & Quantitative Frameworks

Use of frameworks help guide the critiquing process and provide the structure and organization needed in order to accurately and systematically review articles. A critique is an evaluation of the strengths and limitations of the research that is being reviewed. Objectivity must be maintained throughout the critiquing process (Coughlan, Cronin & Ryan, 2007).

Quantitative framework

Through the collection and analysis of numerical data, quantitative researchers test relationships and differences between variables and seek a cause and effect interaction of a particular phenomenon under study (LoBiondo-Wood, & Haber, 2013). For the quantitative articles under review, Coughlan, Cronin and Ryan's (2007) guide to critiquing quantitative research was used. The elements which influence the believability of the research, as well as the elements influencing the robustness of the research, was captured by applying each quantitative

study in a table adapted from Coughlan, Cronin and Ryan (2007) (See Appendix A). As recommended by Whitemore & Knafl (2005), a calculation of quality scores was tabulated in order to ensure the believability and robustness of the research. This process was an in-depth examination of the research under review. The review process was not a criticism seeking only limitations, but an objective approach with the purpose of highlighting the articles strengths and weaknesses, and to identify its trustworthiness (Coughlan, Cronin & Ryan, 2007).

Qualitative framework

For the qualitative articles, Ryan, Coughlan and Cronin's (2007) guide to critiquing qualitative research was used. In qualitative research, truth is not regarded as objective, but a reality that is subjective and is experienced differently by each individual (Ryan, Coughlan & Cronin, 2007). In qualitative research, researchers are not meant to generalize data but to explore individual human experiences (LoBiondo-Wood, & Haber, 2013). Qualitative researchers follow the assumption that multiple realities exist and these realities are created by the research participants (Ryan, Coughlan & Cronin, 2007). The characteristics, approaches, the elements which influence the believability of the research, as well the elements influencing the robustness of the research, was captured in a similar constructed framework as that which was used for the quantitative articles (See Appendix B).

Chapter 3: Findings

Experiences of Shame

Patients with IBD undergo periods of physical and psychosocial adjustment, as do others who are living with chronic conditions; however, those with IBD, often feel an additional weight of shame (Trachter, Rogers & Libeler, 2002). Shame is an uneasy emotion that is experienced when a central feature of the self is thought to be inadequate or inferior; these emotions can be further aggravated by the thought that others too, perceive these imperfections or inadequacies (Dickerson, Gruenewald and Kemeny (2004), as cited in Gilbert, 1997; Tangney, 1995). Shame brings to the forefront a sense of deficiency in one's self (Pines, 1987). "Shame results when perceptions of negative *social evaluation* are transformed into negative *self-evaluation*" (Dickerson, Gruenewald & Kemeny, 2004, p.1195). Experiences of shame for those with IBD can stem from the unpredictable nature of the disease; the embarrassing and socially taboo nature of IBD symptoms; and the unwanted outwardly physical changes related to treatment and medication side effects (Saunders, 2014).

Feelings of shame and its impact on self-concept and adaptation are overarching in the IBD literature reviewed. The experience of shame interferes with having a positive self-concept; which according to Roy (2008), is defined by a composite of beliefs and feelings that individuals have about themselves. These feelings and beliefs are developed through both internal perceptions, and by the perception of others (Roy, 2008). Self-concept is central to each individual; meeting the needs of the physical and personal self are vital to positive adaptation (Roy, 2008). My review of the literature reveals that body image, alterations in sexuality and fears of rejection all contribute to experiences of shame.

Body image

Body image is a central component of self-concept (Roy, 2008). Body image concerns and its influence on adaptation were evident in eight of the 14 articles reviewed. The following factors were influential on self-image and poor adaptation: outward physical changes related to medication side effects; embarrassing IBD symptoms; and the changes to the body associated with the ostomy itself (Allison, Lindsay, Gould, & Kelly, 2013; Krouse et al, 2007; Savard & Woodgate, 2009). The stoma and ostomy were described by some in the literature reviewed as *disgusting* and *ugly*. There were also self-perceptions of being *disfigured* and *damaged* (Notter & Burnard, 2006; Savard & Woodgate, 2009; Sinclair, 2009). For some patients, the change in altered body appearance and the shock of seeing the stoma for the first time was a source of long lasting emotional distress (Notter & Burnard, 2006; Sinclair, 2009). A contributing factor in the experience of shock was associated with the patient not being adequately prepared for what to expect postoperatively (Notter & Burnard, 2006; Sinclair, 2009).

In a comparative descriptive study comparing quality of life in cancer and non-cancer patients undergoing colostomy formation, both groups had a level of dissatisfaction with their body image; however, it was noted that individuals' perception of their body image was more negative in the non-cancer group (Krouse et al., 2007). Possible reasons for this could be the underlying diagnosis of IBD and the nature of the unwanted symptoms (Saunders, 2014). Also, those with IBD may believe they are less healthy, living with the continued unpredictability of disease exacerbations and remissions; whereas, considering the length of time since surgery (Mean 135.9 months) cancer patients are likely to be cured of their disease, and that living with an ostomy may (for some patients) be a small price to pay in their survival (Krouse et al., 2007). Another possibility associated with body image dissatisfaction, could be correlated with gender;

Seventy six of the respondents in the benign group were female (Krouse et al., 2007). Women are affected by body image concerns and tend to be more self-critical and socially compare themselves to others more than men (Franzoi, 2012). For both men and women, experiences of body dissatisfaction is often contingent upon how one focusses upon the cultural influences of physical attractiveness; women tend to be more affected by social and self-scrutiny and cultural standards than men (Franzoi, 2012). Sex and gender are often used interchangeably; however, gender refers to socially constructed factors that a society considers appropriate, such as roles, activities, attributes and behaviours (WHO, 2014). Gender is understood as “a social construct, a multidimensional determinant of health that intersects with culturally prescribed and experienced dimensions of femininity and masculinity” (Bottorff, Oliffe & Kelly, 2012, p. 435). The societal pressure for women to have a “perfect” and unmarked body contributes to body dissatisfaction and altered sexuality in women with IBD and an ostomy (Notter & Burnard, 2006). These findings of altered sexuality are in accordance with Allison, Lindsay, Gould and Kelly (2013), who state that women had a more difficult time accepting the change in body appearance related to scaring and ostomy formation than men. And that women worry about the consequences of surgery in terms of their attractiveness to actual and potential partners, as well as concerns surrounding fertility and pregnancy (Allison, Lindsay, Gould & Kelly, 2013). The influence of sex and gender on health and illness is complex (Bottorff, Oliffe & Kelly, 2012). How feminine and masculine identities can be altered by physical, sexual and social changes are important factors to consider in better understanding patient health-related experiences (Bottorff, Oliffe & Kelly, 2012).

Sexuality

The needs of the physical self within Roy's mode of self-concept consist of, but are not limited to, physical functioning and sexuality (Roy, 2008). Many factors can contribute to ineffective sexual functioning, such as the pathophysiology of disease, social interactions and medication side effects (Roy, 2008). Concerns with sexuality were identified in seven of the 14 studies reviewed as important features of the experience of living with IBD and an ostomy. These factors appear to contribute to ineffective adaptation. Carlsson, Bosaeus, and Nordgren (2003) conducted a study to describe worries and concerns of IBD patients with an ileostomy; findings from their study identified intimacy, loss of sex drive and sexual performance as the area of greatest concern that need to be further addressed in clinical practice. For some patients post-operative nerve damage could play a role in both female and male satisfaction and sexual performance; it was also noted that male stoma patients experienced erectile dysfunction; and approximately 50% (of both male and female patients) were sexually inactive after surgery (Krouse, et al, 2007). The inability to sexually perform impacts upon one's self-concept and can contribute to feelings of shame and inferiority (Pines, 1987). Feeling desirable and sexually attractive affected women more than men (Allison, Lindsay, Gould & Kelly, 2013; Notter, & Burnard, 2006; Sinclair, 2009). The societal pressure for women to be "perfect" negatively impacts and threatens ones sense of self (Savard & Woodgate, 2009). One woman described feeling less feminine, and questioned whether anyone would want to touch her; what would her husband think, and would he still want her; while another patient described a feeling of being less of a woman (Notter & Burnard, 2006). In a narrative inquiry by Sinclair, six out of the seven participants believed the ostomy had negatively affected them sexually. Of those who were married, one participant shared her thoughts of wondering how different this experience would

be if she were single; imagining having to experience dating was impossible. Of those participants who were single, dating and intimate relationships were avoided (Sinclair, 2009).

Fear of rejection

The ultimate goal for most people with an ostomy is to be accepted into the “dominant culture”, which is defined as those without an ostomy (Frohlich, 2012). Many patients fear that they will face rejection from friends, family and members of the community (Frohlich, 2012). According to Roy (2008), adaptation is a complex process that involves a purposeful and cohesive integration of both the person and environment. In order for acceptance to ensue, both the *role function mode*: which focusses in on social integrity, interaction and knowing who one is in relation to others; and the *interdependence mode*: where communication, relational integrity and the feeling of security is formed through secure relationships need to be evaluated. Those who achieve adaptive interdependence have learned to live successfully through the reciprocal nature of giving and receiving with significant others as well as with support systems (Roy, 2008). Self-disclosing their illness comes with a degree of personal risk associated with the fear of judgment and rejection (Allison, Lindsay, Gould & Kelly, 2013; Frohlich, 2012, Frohlich, 2014; Savard & Woodgate, 2009). When IBD patients share information about their disease they open the door to either finding support, or they may attract unwanted stigma (Frohlich, 2014). IBD is largely an invisible illness. Stigmatization in those with IBD is unlike stigmatization in visible medical conditions such as obesity or physical disabilities. Visibly stigmatized individuals worry about how others will behave towards them, and how their “negative” attribute is being perceived and evaluated (Smart & Wegner, 1999). There is very little control that one has over another’s perception. On the other hand, those who have a concealable stigma may be able to hide themselves in social situations; however, the struggle to suppress something

important about themselves comes with psychological cost and psychosocial conflict (Smart & Wegner, 1999). The preoccupation with secrecy and the internal management of intrusive thoughts can be mentally taxing, such that performance and cognitive tasks can be affected.

According to Goffman (1963) as cited by Berger, Ferrans and Lashley (2001), “stigma refers to both the trait and to the outcome of being known to possess that trait” (p. 519). Negative social meanings of an attribute, such as the socially abhorrent bowel symptoms which coincide with IBD as well as the *ostomy* itself become traits of the individual. Based upon these traits, the person can then be stigmatized by a culture or society (Goffman, 1963, as cited by Berger, Ferrans & Lashley, 2001). Some people may conceal their trait in the hopes of passing as “normal”; however, they may suffer from their own perception of being flawed. Wondering how others will perceive them influences individuals’ self-esteem, promotes a negative self-concept and encourages social withdrawal (Goffman, 1963, as cited by Berger, Ferrans & Lashley, 2001). Social withdrawal was evident in eight of the studies reviewed. Young adults living with IBD and an ostomy often fear that they are being judged or looked upon as being different from their peers. This fear contributed to delayed adaptation. The avoidance of activities, attention to wardrobe choices and being careful to not to wear styles that might draw attention to the ostomy exacerbated their feelings of being different, placing them further outside the peer culture (Allison, Lindsay, Gould, & Kelly, 2013; Savard & Woodgate, 2009; Sinclair, 2009).

Embarrassing symptoms, lack of privacy or the feelings of being different can contribute to the feelings of being stigmatized (Notter & Burnard, 2006; Savard & Woodgate, 2009). Savard and Woodgate (2009), in a hermeneutic phenomenological study on understanding the lived experiences of young people living with ulcerative colitis and a temporary ostomy, found that stigma was part of the experience of living with IBD (Savard & Woodgate, 2009). In a study

by Notter and Burnard (2006), one patient spoke about how the disposal of ostomy bags in her area was handled the same as clinical waste. The bright yellow bags robbed her of her right to privacy, and made her feel that her IBD and ostomy was shameful, that there was something for others to fear.

According to Goffman (1963), “the stigmatized and the normal are part of each other: if one can prove vulnerable, it must be expected that the other can, too” (p.135). Frohlich (2014), in a phenomenological study on understanding individuals’ experience of IBD during the course of their disease, found that the support patients received far outweighed the stigma that they experienced. Being surrounded by a supportive network, keeping perspective and not living life in isolation, but taking proactive steps to disclosing their IBD, seemed to play a role in diffusing situations of stigma (Frohlich, 2014). Self-disclosure to society comes with a set of risks, one of them being acceptance (Frohlich, 2014).

Experiences of shame for those with IBD and an ostomy was associated with body dissatisfaction, alterations in sexuality and fears of rejection. These factors had a profound impact on self-concept and hindered positive adaptation. IBD and the ostomy itself were not mutually exclusive, but contributed together to the experiences of shame.

The Need for Social Connectedness

Social connectedness is an “internal sense of belonging and is defined as the subjective awareness of being in close relationship with the social world” (Lee & Robins, 1998, p.338). The feeling of security that comes from acceptance, protection and a nurturing connection enhances the relational integrity of a relationship while strengthening the adaptive process (Roy, 2008). The interdependence mode within Roy’s adaptation model refers to the value of close relationships, the ability to give and receive respect, value and love. It involves effective

communication and having an adequate social support system (Roy, 2008). Satisfying personal relationships with others encourages a sense of security and promotes relational integrity (Roy, 2008). Interdependent relationships are categorized into two groups, support systems and significant others. *Support systems* according to Roy, include “persons, groups, and organizations with which one associates in order to accomplish goals or achieve some purpose” (p. 385); this can include, healthcare professionals as well as community support systems. *Significant others* are identified as those who are valued more than any other relationship; these can include family members, a spouse, parent, friends and God (Roy, 2008).

The need for social connectedness was a predominant feature in the literature reviewed. Both the positive aspects of connectedness, as well as the impact of social disconnect, was discussed in association with the relationships between partners, friends and family. The need for social connectedness was also evident in the relationships formed between healthcare providers and fellow IBD ostomy patients.

Support systems

IBD patients shared their experience of support received by healthcare professionals. Several shared how they felt supported and valued by relational connections, compassion and empathetic care (Frohlich, 2014; Sinclair, 2009). Emotional and practical support was a key factor with positive adaptation. One patient described her nurse as *amazing* and a reliable unwavering support (Allison, Lindsay, Gould, & Kelly, 2013). Patients found that the path towards healing was encouraged by those nurses who provided reassurance, spent time and encouraged them to discuss feelings and concerns (Notter & Burnard, 2006).

On the other hand, some patients experienced negative encounters with nurses and other healthcare professionals; this interfered with adjustment to living with IBD and an ostomy

(Notter & Burnard, 2006; Sinclair, 2009). Some of these experiences included feeling uncomfortable and shamed by healthcare practitioners. For example, this was evident when nurses showed unintentional, but obvious and subtle displays of disgust for the ostomy. One patient shared thoughts that it must be really bad if a professional nurse was *turned off* by the ostomy. This left the patient wondering how others outside the hospital would react (Sinclair, 2009). There were others who felt dismissed, uncared for, and disrespected when their voice was unheard. This was especially true when faced with healthcare professionals lacking in empathy (Allison, Lindsay, Gould, & Kelly, 2013; Sinclair, 2009).

There are instances in the literature where a disconnect between the patient and healthcare practitioner caused conflict and distress (Allison, Lindsay, Gould, & Kelly, 2013). The lack of both decision making control and the opportunity to voice concerns and opinions was not only upsetting, but in some instances dangerous, resulting in surgeries being delayed or even refused (Allison, Lindsay, Gould, & Kelly, 2013). Patients have lived with their chronic condition of IBD, often for a long period of time; and believed they had a valid contribution to say what was “best for them” and to be involved in the decision and direction of their care (Allison, Lindsay, Gould, & Kelly, 2013).

Value of peer connections

The value of peer connectedness was mentioned throughout much of the literature. Many patients valued the interaction and learning through connecting with other patients who had undergone the same surgical procedure; this was evident in seven of the studies reviewed. Positive connections facilitated increased knowledge, improvement in decision making capabilities and reduction in anxiety (Sinclair, 2009). Bringing together patients of similar age assists in meeting the unique needs of the IBD patient and gives them opportunity to share and

discuss. For those IBD patients who have lived with IBD and an ostomy, sharing stories and providing support can help a new ostomate through some of the challenges and help in directing them towards greater adaptation. Peer connections were achieved through various avenues such as one-on-one meetings; IBD and ostomy support groups, and online internet chat rooms (Allison, Lindsay, Gould, & Kelly, 2013; Frohlich, 2012; Krouse et al, 2006). Interaction with their peer community increased awareness and relational closeness for IBD patients and reduced feelings of isolation (Frohlich, 2012). Having a community of support not only provided encouragement but also a sense of belonging (Coulson, 2013). For example, online communities of support provided emotional and informational support and contributed to an improvement in general-well-being (Coulson, 2013). The participation in face to face peer support groups could also enhance psychological recovery and offer a sense of comfort and acceptance (Huddleston Cross & Hottenstein, 2010).

Etienne Wenger discussed the concept of *communities of practice* and supported the value and importance of much needed peer support and relations within patient communities. “Communities of practice are formed by people who engage in a process of collective learning in a shared domain of human endeavor” (Wenger, 2011, p.1). According to Wenger, three factors are crucial for an effective community of practice: First, is the *domain*, which is identified by a shared area of interest and commitment, in this instance the shared area of interest is living with IBD and ostomy. Second is the *community*, where members discuss and build relationships and learn from one another. For example, the opportunity to connect and form relationships with other IBD patients. Finally the third characteristic is the *practice*, which is not only a community of shared interest, but practitioners with a repertoire of tools, stories and ways to manage recurring problems. This is an opportunity, once the relationship is formed, to share challenges

and victories, and to communicate strategies that assisted towards adaptation (Wenger, 2011). IBD patients need other IBD patients; having the opportunity to connect, share, provide mutual support and learn alongside one another is essential towards adaptation. Matching a colorectal cancer ostomate with an IBD patient may not be appropriate, nor relevant and could further impair the path towards successful adaptation.

As mentioned earlier, satisfying personal relationships with others encourages a sense of security and promotes relational integrity (Roy, 2008). Having a sense of connectedness and belonging with those who share a supportive role can help towards building strength and confidence in the intimate relationships shared with significant others.

Significant others

The importance of interpersonal relationships and the value of feeling supported by those closest was evident in nine out of 14 articles reviewed. Social dimensions of life such as family, friends and an active social and leisure life were considered important factors in quality of life with an ileostomy (Carlsson, Bosaeus, and Nordgren, 2003). Romantic relationships were also an immense support, and are considered to be the greatest source of support for those in a committed relationship (Frohlich, 2014). Several women reported that reassurance of supportive husbands was integral to their ability to cope. Some women described their husbands as wonderful; one husband was referred to as *magic* for still wanting to be intimate while she still had the ileostomy (Notter & Burnard, 2006, p.153). Maintaining friendships and interpersonal relationships was vital and considered by many as the most needed and important support system (Perry-Woodford, 2013; Sinclair, 2009).

We cannot underestimate the importance of support, counselling and education for both the patient and the family. Inadequate support can lead to issues related to self-concept and

compound feelings of shame hindering positive adaptation. Information discontinuum and the lack of educational materials, teaching and support from healthcare professionals was evident in seven of the 14 articles reviewed. This lack of connectedness related to information transfer to patients and families caused distress (Notter & Burnard, 2006; Perry-Woodford, 2013; Sinclair, 2009). For example, several women in Notter and Burnard's qualitative study on the experiences of loop ileostomy surgery reported that their levels of distress increased when their partners and families saw them for the first time post-operatively. The sight of a loved one post-operatively can be a daunting experience (Notter & Burnard, 2006). This speaks to the importance of offering support not only to patients but also their families. It was reported that those who had difficulty managing and accepting their partner's post-operative state were not offered pre and post-operative counselling. Some partners were involved in preoperative teaching and counselling, making it somewhat easier to support their loved one. However, the majority were not, perhaps in this case, this is related to the ostomy being a temporary measure (Notter & Burnard, 2006). This lack of inclusion contributed to patients' distress and hindered adaptation. Family are considered the "pillars" of support (Perry-Woodford, 2013), when the family is not adequately prepared the patient's recovery process is weakened.

The interdependence mode of Roy's adaptation model supports the fact that, without the social connectedness of an adequate support system and the love and encouragements of significant others, relational integrity and adaptation cannot ensue. Social connectedness stems far beyond one's inner circle. The value of both the patients' inner and outer worlds of support are vital elements towards positive adaptation.

The Resolve to Live Again

Loss is a common theme throughout life. People experience loss for a number of reasons, a few being the loss of a loved one, the loss of a relationship or a loss of health. Dealing with a significant loss is difficult and grieving for a loss is a natural process towards positive adaptation. Grief can be transformative in that it can facilitate healing and lead one to a higher level of personal integrity (Roy, 2008). The experience of loss is unique to the individual, and each person follows his/her own grieving trajectory. For IBD patients, the experience of loss associated with undergoing colorectal surgery, can stem from alterations in body image, or change in the body's function; to the anticipated loss in sexuality and feeling desirable.

Grief and loss can occur in all four of Roy's adaptive modes (Roy, 2008). First, the loss in one's physical ability to evacuate normally influences the *physiological mode*; for some the loss in the ability to naturally control their bowel function can be very troubling (Notter & Burnard, 2006). Second, loss in the *self-concept mode* for a person with IBD and ostomy can be related to an alteration in body image or the potential loss in sexuality. A loss within the *interdependence mode* can occur if a relationship becomes strained or breaks down due to the result of surgery. Finally, role *function* can be affected by how IBD and the ostomy influences how one is perceived in society. Grief is a compensatory adaptive processes and Roy postulates that for adaptation to occur, one passes through four stages of grief: shock and disbelief; apprehending the loss; attempting to deal with the loss; and finally, final restitution and resolution (Roy, 2008).

Shock and disbelief

Roy describes disbelief or denial as a feeling of shock or the overpowering feelings of loss. Loss can be potential or actual (Roy, 2008). For example, IBD patients may feel a tremendous *actual* loss in wellness when first diagnosed with a chronic condition. For those who may undergo surgery and ostomy formation *potential* or anticipatory grief may be present. It is important to note that patients can be experiencing grief at any point during the trajectory of their disease.

Feelings of denial are important, and are there to protect the psyche from being overwhelmed (Kübler-Ross & Kessler, 2005, Roy, 2008). Denial was evident through patients' desire to keep their early experiences with IBD a secret, in the hopes that the symptoms would "just go away" (Savard & Woodgate, 2009). Some patients discussed how they avoided medical care for years and circumvented discussions of what was or what could be wrong (Allison, Lindsay, Gould & Kelly, 2013). Others described knowing that surgery was essential but felt unready, and had difficulty in "take things in" (Perry-Woodford, 2013, p. 27). Feelings of shock presided in the early postoperative period. Some avoided looking at the ostomy, one patient *never* looked at the ileostomy; her mother provided stoma care until the ostomy was reversed (Notter & Burnard, 2006). In some instances, healthcare professionals contributed to patients' feelings of denial which often led to patients' difficulty with caring for their ostomy. While hospitalized, some patients felt pressure from healthcare professionals to "hurry up" and engage with this care. Many of these young adults felt unready to take responsibility for an ostomy that they never wanted in the first place (Savard & Woodgate, 2009).

Whether this expression of denial is considered adaptive or ineffective depends upon the duration of the experience (Roy, 2008). Adaptive responses are those that promote integrity of

the human system (Roy, 2008). If denial has served as a protection from feeling overwhelmed then to some degree this response is adaptive. If on the other hand, experiences of denial impact upon emotional wellness and increase physical risk then the integrity of the human system is in jeopardy and adaptation can be ineffective.

Apprehending or taking hold of the loss

Apprehending or taking hold of the loss can present itself through the expression of distress, fear and anger (Roy, 2008). Anger was a common experience and was illustrated with phrases such as: “*why me*” and “*what did I do to deserve this*” (Savard & Woodgate, 2009). For some, anger was shared over ostomy leakage, believing that the problems associated with bowel incontinence was finally gone (Sinclair, 2009). A young woman with Crohn’s disease and an ileostomy expressed anger not only with the loss of intestine, but also with the need to endure a chronic illness (Sinclair, 2009). Anger was expressed in how “*life was unfair*” and that life in general was being missed out on because of their medical condition. Anger is a normal reaction to loss and a necessary part of the healing and adaptation process (Kübler-Ross & Kessler, 2005). Voicing feelings of anger helped patients move past feelings of denial. Encouraging and permitting patients to express their emotions promoted their ability to move forward with their condition. Taking hold of the loss is an integral part of their healing process.

Attempting to deal with the loss

In terms of the role of loss in adaptation, Roy (2008) posits that feelings of anxiety and depression, and expressions of sadness and despair are to be expected in one’s attempts at dealing with loss. Depression and anxiety can contribute to a poor self-concept which can be a barrier to adaptation. There is loss in feeling whole, a loss of enjoyment with life and a loss in the desire to connect with others; all of these factors can impact one’s self-concept. Depression

and anxiety were evident in many patients with IBD and ostomy (Krouse et al., 2007; Knowles et al., 2013). Anxiety and depression was higher in those ostomates without cancer (Krouse et al., 2007). It was also noted that temporary stoma patients suffered more depression and anxiety than permanent stoma patients (Knowles et al., 2013); and many of those with a temporary ostomy lost out on living by restricting life until the reversal (Allison, Lindsay, Gould, & Kelly, 2013; Notter & Burnard, 2006). Anxiety is an important aspect of loss. Anxiety can affect one's self-consistency which relates to having equilibrium in life and self-organization (Roy, 2008). For those with Crohn's disease, worry over disease recurrence was evident in a number of studies and was a contributing factor with psychological disturbance (Knowles et al., 2013; Krouse et al., 2007). Feelings of depression, anxiety and worry are a normal part of dealing with one's loss (Roy, 2008). These feelings may never fully go away, but managing these feelings can open the door to restitution and resolution.

Final restitution and resolution

Final restitution and resolution involves the person having a positive interest in life after the loss (Roy, 2008). A positive adaptive response supports the notion that the integrity of the human system has become (or is starting to become) integrated and whole (Roy, 2008). Having resolution or acceptance is not always about liking a situation; it may mean for some simply having a few more good days than bad (Kübler-Ross & Kessler, 2005). Recognizing that learning to live with a new reality is part of acceptance (Kübler-Ross & Kessler, 2005). Most people living with an ostomy recognize that it is not an ideal situation (Frohlich, 2014) and most wish that they never had the ostomy (Sinclair, 2009); however, for most, the fecal diversion provided relief of burdensome IBD symptoms and assisted towards adaptation and an improved quality of life (Kasperek, et al, 2007; Frohlich, 2014). A *renewed sense of self* was expressed by

a number of patients in this review; this renewal was related to pain relief and feeling healthy, a feeling that many patients had not experienced for a long time (Savard & Woodgate, 2009). One patient described surgery as a *rebirth* or a chance to focus on living with a renewed perspective (Sinclair, 2009). Young patients that underwent a reversal of their stoma were more likely to adapt and connect with being “normal”. On the other hand, *living again* was described by one patient as the best part of having a permanent ileostomy (Allison, Lindsay, Gould, & Kelly, 2013; Sinclair, 2009). Time was also identified as a major factor in adjustment (Allison, Lindsay, Gould, & Kelly, 2013; Sinclair, 2009).

Comparing their experiences after surgery from before contributed to patients’ adaptive process. Generally, reflecting on how poorly they had felt prior to surgery contributed to a sense of wellness. A central element in adjustment came from having a positive outlook and ability to see the positive changes the stoma had brought; such changes included a renewed feeling of health, improved quality of life and ability to make plans for the future (Allison, Lindsay, Gould, & Kelly, 2013). Acceptance also came easier through interacting and connecting with others (Allison, Lindsay, Gould & Kelly; Sinclair, 2009). Knowing that there were other IBD ostomates within the community helped to reduce feelings of isolation (Frohlich, 2012).

Adaptation is an active process that requires a consciousness of determination, a self- awareness and an environment of support (Roy, 2008). Transitioning towards adaptation takes patience and time. One patient with Crohn’s disease described for the first time since his diagnosis that he was now *living a life instead of existing* (Knowles et al., 2013, p. 626). An ostomy can bring renewed health and wellness, and a resolve to live again.

Chapter IV: Discussion

Summary of the Findings

The findings of this integrative review provide a greater understanding of the challenges and struggles with adaptation that IBD patients face. The findings also highlight the strengths and positive changes an ostomy brought to the lives of IBD patients. Three themes emerged from the analysis of the literature: First, *the experiences of shame* and its impact on self-concept; second, *the need for social connectedness* and the value of relationships; and finally, *the resolve to live again* and how patients move through grief.

The experiences of shame

Self-concept is central to each individual; meeting the needs of the physical and personal self are vital to positive adaptation (Roy, 2008). Particularly important concerning one's self concept was the experience of shame. Shame was associated with body dissatisfaction, alterations in sexuality, fear of not being accepted by those without an ostomy and worries surrounding potential stigma. The unpredictability of the disease combined with the embarrassing and socially taboo nature of IBD symptoms can disrupt a person's self-concept. These factors, coupled with the potential for the IBD to become outwardly apparent with physical changes related to treatment, can further disrupt one's self-concept in terms of shame and perceived stigma (Saunders, 2014).

The need for social connectedness

Social connection was part of the adaptive process. Social connections were categorized into two groups: *support systems* and *significant others*. Support systems include healthcare professionals and community peer relations. Significant others included friends, family and romantic partners. Positive and negative experiences of connectedness were shared. Positive

experiences in social connectedness included engaging with practitioners who encouraged an open dialogue, where active listening and empathic care presided. IBD patients expressed that peer connections and a belonging to a community of practice was a positive experience in meeting their unique needs. The social connectedness with significant others was an area of immense support. For some patients, disconnect ensued was when the healthcare provider lacked empathy, and where patients felt an absence in decision making control. Other areas where disconnect presented was in terms of information transfer to both patients and family members, and in the discontinuum in and educational needs and concerns. It was clear in the literature that satisfying personal connections promote relational integrity and in turn adaptation.

The resolve to live again

Experiences of loss and grief associated with living with a chronic illness and an ostomy was the third theme that emerged from my analysis. Roy's adaptation model associated with four stages of grief: shock and disbelief, apprehending the loss, attempting to deal with the loss and final restitution and resolution (Roy, 2008), all clearly demarcated the behaviours and experiences that a patient may be experiencing. Feelings of disbelief, anger, depression and frustration were shared. Moving through these feelings of grief for many brought forth acceptance to life with an ostomy. Seeing life through a lens of positive change and through experiences of renewed health also contributed to positive adaptation.

Limitations

There were limitations in conducting this integrative review. Every effort was made to include all relevant articles. An ancestry search was done in order to capture articles that were not evident in the database search. All studies were peer reviewed and were performed with ethical integrity. One descriptive phenomenological study by Notter and Burnard (2006) did not

stipulate ethical provisions, however, given the credentials of the researchers it can be assumed that the study was conducted with human research ethics approval. Small sample sizes were regarded as limitations in three of the quantitative studies reviewed (Camilleri-Brennan, Munro & Steele, 2003; Carlsson, Bosaeus & Nordgren, 2003; Kuruvilla, Osler & Hyman, 2012). The knowledge generated from these cohorts could not be generalized.

A limitation in four of the eight qualitative articles reviewed was the use of a single participant interview (Allison, Lindsay, Gould & Kelly, 2013; Notter & Burnard, 2006; Perry-Woodford, 2013; Sinclair, 2009). A single interview may not have fully captured patients' experience of living with an IBD and an ostomy. Credibility of the study was also compromised in the qualitative studies reviewed; member checking occurred only in one of the articles (Sinclair, 2009). Bracketing and reflexivity was not mentioned in the majority of the qualitative articles reviewed.

As discussed, quantitative and qualitative research has its limitations. The studies included in this review had some limitations but no major flaws were identified that would prohibit inclusion into the review. Nevertheless the findings provided valuable insight into living with IBD and an ostomy.

Summary of the Methodology

The integrative literature review using Whittemore and Knafl's (2005) five step process was the chosen methodology for this project. Fourteen peer reviewed research articles were included (seven qualitative) and (seven quantitative) in the review. Pertinent data was extracted from the articles and organized into a qualitative and quantitative research framework adopted from Coughlan, Cronin and Ryan (2007) (See Appendices A & B). Each article was scored for robustness and believability. A summary of each article was created capturing the study's ethical

factors, methodological design, sample, setting, population size, data collection, data analysis, the applicability to theory, strengths and limitation and findings and implications for practice (See Appendix C & D). A concept map was created capturing repeated words, ideas, phrases and themes. Through this review process a reflective journal was also kept.

Summary of the Theoretical Model(s)

Roy's Adaptation Model

Roy's Adaptation Model was chosen as a theoretical lens to inform this integrative review. The findings from this review capture and validate the usefulness of this model. Analyzing and reviewing the literature using this theoretical lens helped in further understanding the process of adaptation related to living with IBD and an ostomy. Life with a chronic illness such as IBD is an ever evolving and ongoing process where adaptation is directly related to the integrity of the entire human system in becoming integrated and whole (Roy, 2008). Roy posits that optimal health and well-being is a process and a state of being contingent upon how we positively integrate, interact and adapt within our changing internal and external, social and physical environment (Roy, 2008). Of importance is that people never act in isolation but are influenced by the environment and the interaction between people and their world; this in turn affects the environment (Roy, 2008). From this review, self-concept, relational integrity and the need for social connectedness were essential components to adaptation.

Relational Ethics

A relational ethics lens also helped to inform this study and brought to the forefront the importance of relational practice. Relational ethics included the patient-practitioner connection and those involving interpersonal and peer relations. Supportive and significant relationships in this study had an essential impact on patients' adaptation processes. "Roy's adaptation model

links to the concept of relational ethics. Relational ethics involves bringing together human compassion and scientific knowledge; it involves mutual respect and the importance of valuing ones differences; it also involves trust and relational engagement where personal connection and shared moments give way to seeing and interpreting situations together (Bergum, 2013). The feeling of security that comes from acceptance, protection and a nurturing connection, enhances the relational integrity of a relationship while strengthening the adaptive process (Roy, 2008). This connectedness was a central aspect of patients' adaptive process.

Implications for Practice

Based on the literature and my own practice the following are suggestions for advance nursing practice.

Implications for Advance Practice

Difficulties in adapting to IBD and an ostomy are multifactorial. As patients traverse towards adapting to this change in life, advanced practice nurses play a key role in helping patients and families manage these challenges. Some of the areas that need to be followed in those with IBD and an ostomy are: sexuality, body image, and social functioning (Kuruvilla & Osler, 2012).

Sexuality and body image

Sexuality and body image concerns need to be addressed both pre and post-operatively (Allison, Lindsay, Gould & Kelly, 2013; Carlsson, Bosaeus & Nordgren, 2003; Krouse et al, 2007). Many nurses may feel hesitant, fearful or ill prepared to approach issues of sexuality; however, addressing these concerns is a fundamental part of holistic and contemporary patient care (Huang, 2013). Some healthcare practitioners may wait for the patient to bring up issues surrounding their sexual well-being. If patients don't raise the discussion, practitioners may

equate silence with having no concerns. Patients may think that the lack of inquiry means that it's not appropriate to discuss issues of sexuality (Taylor & Davis, 2007). A tool that has been used to help identify an individual's sexual well-being is Davis and Taylor's (2006) Ex-PLISSIT model. The model is an extension to the PLISSIT model that was created by Annon (1976) for practitioners to identify and help address patients' sexuality concerns. According to Taylor and Davis (2006), the Ex-PLISSIT model has four levels of intervention. The first stage is *Permission (P)*, which involves providing the opportunity and explicit *permission* to freely discuss sexual concerns; it also involves assessment and normalizing sexuality. The second stage is, *Limited Information (LI)*, where information is shared on how chronic illness and certain treatments can affect sexuality. Dispelling myths and giving factual information is essential in this stage. The third stage is *Specific Suggestions (SS)*; this is a problem solving stage where all aspects of sexuality are addressed rather than just sexual behaviour. For example, a young woman with IBD and an ostomy may feel a sense of loss associated with both the diagnosis of a chronic illness and/or the surgery itself. She may feel a loss in self-concept related to her altered body appearance, and she may feel less feminine or less sexually attractive. Suggestions need to be made to meet the individual needs of the patient. For example, the practitioner can discuss what femininity means to the patient and what enhances these feelings (Taylor & Davis, 2006). Through relational practice and active engagement suggestions can be discovered collaboratively. The final stage is *Intensive Therapy (IT)*; for some patients advanced psychosexual counselling may be required. It is essential for the nurse to recognize when a situation may be outside one's training and scope of practice. For example, in situations of abuse or when relationship problems surface the patient needs to be referred to the appropriate psychological service.

Advancing nursing practice in this area can be met through attending advanced practice seminars and advancing skill through formal psychosexual education. According to Sinclair (2009), psychosexual nursing education and addressing patients sexual concerns can help with the adjustment to living with IBD and an ostomy.

Social functioning

Effective social functioning and connectedness is essential towards positive adaptation. Nursing should be assessing the type and extent of patients' social support. By taking the time to inquire about the patients support networks and psychosocial well-being, the advanced practice nurse (APN) can determine potential barriers as well as what can promote adaptation. Communication and social interaction can be adversely affected by both IBD and the ostomy. Some patients are hesitant to talk with others for fear of judgement; this can perpetuate feelings of being different and promote isolation. Patients can find that revealing and self-disclosing information about their ostomies to others is difficult (Frohlich, 2012). Taking time to allow patients to share their stories can help build patients' confidence towards sharing and disclosing with others. Developing social links and support groups assist in decreasing isolation and improve adaptation. For example, arranging a meeting with other IBD patient of the same age who has undergone the same experience can promote feelings of belonging and promote relational connectedness.

Understanding how patients communicate and obtain information is important for APN's to attend to. Some patients may prefer the anonymity of online information and support; others may prefer face-to-face support groups. APN's need to know and listen to the needs of their patients and be up-to-date on reliable information available to meet those needs. Finally, information should also be extended to the family as they are often patients' "pillar" of support

(Perry-Woodford, 2013). Inquiring about the needs and concerns of the family and preparing them for what to expect postoperatively can improve social connectedness with significant others. This is an essential component towards positive adaptation.

Depression and anxiety can also impact social functioning and impinge upon adaptation. Nurses should be skilled in counselling and in understanding mental health issues and be aware of the increased risk for anxiety and depression in this population. Nurses are in a primary position to provide stress management, relaxation and mindfulness techniques; they are well positioned and well qualified to coach patients with learning these techniques.

A positive, empathic, non-judgemental environment promotes effective communication, builds trust and is essential towards creating meaningful connections. Healthcare practitioners need to include patients in the decision making process. They need to actively listen to patients' concerns. Creating a safe environment and conveying a positive attitude can facilitate patients' positive adaptation.

Nursing Ethics

Nursing aims to restore balance and integrity in the human system by supporting and empowering the individual (Lemonidou et al., 2004). Nurses need to be reflective and self-aware of their actions in order to ensure humanistic and ethical practice. It is imperative for healthcare professionals to be cognizant to how negative reactions can impact on another's adaptation and well-being. When patients are stigmatized by the healthcare profession, the experience can be damaging, and its effect can be long lasting (Frohlich, 2014). Healthcare professionals need to be reflective in examining one's own feelings when caring for a patient with an ostomy (Sinclair, 2009). Self-awareness is essential towards a therapeutic nurse-patient relationship.

Implications for Nurse Education

A number of education practices have been identified through the analysis of the literature. Areas of advancing nursing education include the promotion of self-care strategies, information seeking, educating nurses on assessment tools, and the advancement of staff nurse education.

Self-care promotion

Advancing nursing education should include self-care strategies such as relaxation techniques, stress reduction exercises and mindfulness meditation. According to Dudley-Brown (2002) and Jacobson (1967) as cited by (Mizrahi et al., 2012), “relaxation techniques comprise any method, process or activity that helps a person relax, attain a state of calm and reduce levels of anxiety, stress or tension” (p. 1466). Relaxation techniques can include but are not limited to: diaphragmatic breathing, progressive muscle relaxation and guided imagery (Mizrahi et al., 2012). Considering the psychosocial factors associated with IBD and having an ostomy, APN’s are in a pivotal position to teach relaxation techniques to patients to help reduce stress and anxiety and improve quality of life. Some other stress reduction exercises can include, participating in physical activity (as tolerated), spending time with friends, and making time for leisure activities. Mindfulness meditation has been used as complimentary therapy in a number of clinical indications including, but not limited to, depression and anxiety disorders, chronic pain management, and in improving well-being in those with rheumatoid arthritis (Pradhan, et al., 2007). Mindfulness interventions in those with a chronic condition can promote adaptive coping and can reduce physical and psychological distress and improve quality of life (Proulx, 2003). Nurses can be taught how to use these teachings by practicing mindfulness; they also can build their knowledge on such techniques from mindfulness clinicians and practitioners. Self-

care promotion and use of effective self-care strategies are essential towards patients' positive adjustment.

Information seeking

Having a lack of accurate information is a deterrent to positive adaptation (Notter & Burnard, 2006; Sinclair, 2009). Nurse educators should seek out comprehensive written materials, resources and/or educational videos that could be used to help improve patient knowledge and promote adaptation. APN's can access many reputable websites and organizations such as those with the Crohn's and Colitis Foundation of Canada (CCFC), the United Ostomy Association of Canada and the Canadian society of intestinal research. These organizations have provided written and multimedia educational support tools.

Utilizing assessment tools in practice

Educating nurses on various educational strategies and assessment tools such as the Rating Form of IBD Patient Concerns (RFIPC) may be useful in clinical practice. This 25 item questionnaire is designed to assess disease, body, interpersonal and sexual worries and concerns in patients with IBD. Findings from the RFIPC can highlight what specific concerns need to be addressed in clinical practice. Also, educating nurses on the use of the Ex-PLISSIT model can help nurses identify and address patients' sexuality concerns. This model can be used as a platform to encourage patients' to share their feelings regarding alterations in physical function and body image. In order to successfully implement this model, healthcare practitioners need to be cognizant to reflect and review personal attitudes and how these can potentially impact upon the consultation (Taylor & Davis, 2007). The practitioner needs to take a sexual history in order to identify problems, concerns and the patients' expectations so that specific suggestions can be made (Taylor & Davis, 2007). Educating nurses on the EX-PLISSIT tool can take place in the

form of an interactive case study workshop. The model and the four stages can be discussed and case studies from clinical practice can be shared.

Advancement of staff nurse education

Teaching patients ostomy management and self-care is often introduced initially by the enterostomal and wound ostomy nurses. However, during the postoperative period staff nurses are intimately involved in providing patient care. Advance practice nurses need to be involved in educating staff nurses through group teachings, and through in services and seminars. Educating staff nurses on the unique needs of IBD patients builds nursing confidence and can help patients be well informed and appropriately cared for.

Recommendation for Future Research

A number of implications for future nursing research have been identified. For example, a qualitative longitudinal study exploring IBD patients' pre and postoperative experiences of adaptation to an ostomy would increase practitioners understanding of what patients' experience, and could help to inform nurses and other clinicians in providing holistic care. Another area for future nursing research may be a quantitative comparative descriptive study, exploring adaptation with an ostomy for those with colon cancer and those with IBD. By comparing adaptation in these two groups, a greater understanding and insight into their unique differences would advance practice for clinicians working with both populations.

An additional area of research could be the development of a tool to assist in identifying factors that contribute to poor adaptation, and /or predictors for positive adaptation. To be able to assess which IBD patients are at risk for poor adaptation would be a proactive step towards improving health and well-being, and could advance practice for all health professionals caring for IBD patients. Finally, there appears to be a lack of literature capturing the IBD patient's

perspective on body image and sexuality. A qualitative study of both men and women living with IBD could shed light on patient concerns and highlight some of the differences that may be associated with both sex and gender. A broader understanding of body image perceptions of both men and women with IBD would be an important step towards advancing nursing knowledge, as well as towards the development of targeted health care interventions.

Conclusion

My goal of this integrative review was to develop a greater understanding of the experiences of those living with IBD and an ostomy and to bring to the forefront an awareness of the challenges and struggles with adaptation that IBD patients face. The final purpose was to identify recommendations for practice where APN's can support and foster positive adaptation in IBD patients living with an ostomy. I believe the knowledge obtained in this review has provided just that and more. We have seen not only the struggles but the victories and the positive changes associated with the courage to move through grief towards a new beginning and a new life. Analyzing and reviewing the literature using the theoretical foundation of Roy's adaptation model contributed to further understanding the process of adaptation related to living with IBD and an ostomy. The findings also capture and validate the usefulness of Roy's theoretical model and its relevance in nursing practice and nursing research.

The three identified themes in this review, *experiences of shame*, *the need for social-connectedness* and *the resolve to live again*, all speak to the importance of empathy. Active listening and an empathic presence from health care professionals can assist in remedying patients' distressful and maladaptive emotions such as shame. An empathic partnership between patients and practitioners is essential towards collaborative patient centered care. Although a patient may not always return to a previous state of health, the way that a person is able to

positively cope, respond to change, and is empathically cared for can bring about improved health, increased peace and overall adaptation.

References

- Alligood, M., & Tomey, J. (2010). *Nursing theorists and their work*, 7th edition. St Louis, MO. Mosby.
- Allison, M., Lindsay, J., Gould, D., & Kelly, D. (2013). Surgery in young adults with inflammatory bowel disease: A narrative account. *International Journal of Nursing Studies*, 50(11), 1566-1575. doi:10.1016/j.ijnurstu.2013.04.003
- Austin, W. (2006). Engagement in contemporary practice: A relational ethics perspective. *Texto & Contexto Enferm Florianopolis* 15 (Esp), 135-14.
- Bayless, T., & Hanauer, S. (2001). *Advanced therapy of inflammatory bowel disease*. Hamilton, ON: Decker Inc.
- Begoray, D., Banister, E., Wharf Higgins, J., & Wilmot, R. (in press A). Puppets on a string? How young adolescents explore gender and health in advertising. *Asian-Pacific Journal of Health, Sport and Physical Education*.
- Berger, B. E. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24(6), 518; 518-529; 529.
- Bergum, V. (2013). Relational ethics for health care. In J.L. Storch, P. Rodney, & R. Starzomski (Eds.). *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 127-142). Toronto, ON: Pearson.
- Bottorff, J. L., Oliffe, J. L., & Kelly, M. (2012). The gender(s) in the room. *Qualitative Health Research*, 22(4), 435-440.
- Brown, H., & Randle, J. (2005). Living with a stoma: A review of the literature. *Journal of Clinical Nursing*, 14(1), 74-81. doi:10.1111/j.1365-2702.2004.00945.x

- Brydolf, M., & Segesten, K. (1996). Living with ulcerative colitis: Experiences of adolescents and young adults. *Journal of Advanced Nursing*, 23(1), 39-47. doi:10.1111/j.1365-2648.1996.tb03133.x
- Camilleri-Brennan, J., Munro, A., & Steele, R. J. (2003). Does an ileoanal pouch offer a better quality of life than a permanent ileostomy for patients with ulcerative colitis? *Journal of Gastrointestinal Surgery*, 7, 814-819.
- Canavan, C., Abrams, K., Hawthorne, B., Drossman, D., & Mayberry, J. (2006). Long-term prognosis in Crohn's disease: Factors that affect quality of life. *Alimentary Pharmacology & Therapeutics*, 23(3), 377-385.
- Carlsson, E., Bosaeus, I., & Nordgren, S. (2003). What concerns subjects with inflammatory bowel disease and an ileostomy? *Scandinavian Journal of Gastroenterology*, 38, 978-984.
- Crohn's and Colitis Foundation of Canada (CCFC). (2012). The impact of inflammatory bowel disease in Canada: 2012 final report and recommendations. Retrieved from: www.cafc.ca.
- Coughlan, M., Cronin, P., & Ryan, F. (2007). Step by-step guide to critiquing research. Part 1: Quantitative research. *British Journal of Nursing*, (16)11, 658-663.
- Coulson, N. S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM Short Reports*, 4(8), 1; 1-8; 8.
- Cross, H. H., & Hottenstein, P. (2010). Starting and maintaining a hospital-based ostomy support group. *Journal of Wound, Ostomy, and Continence Nursing: Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN*, 37(4), 393-396.
doi:10.1097/WON.0b013e3181e45794; 10.1097/WON.0b013e3181e45794

- Danielsen, A. K. (2013). Life after stoma creation. *Danish Medical Journal*, 60(10), B4732.
- Decker, J. (2000). The effects of inflammatory bowel disease on adolescents. *Gastroenterology Nursing*, 23(2), 63-66.
- Drossman, D. A. (1989). Health-related quality of life in inflammatory bowel disease functional status and patient worries and concerns. *Digestive Diseases and Sciences*, 34(9), 1379; 1379-1386; 1386.
- Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. *Science New Series*, 196(4286), 129–36.
- Franzoi, S. L. (2012). Exploring body comparison tendencies: Women are self-critical whereas men are self-hopeful. *Psychology of Women Quarterly*, 36(1), 99; 99-109; 109.
- Frohlich, D.O. (2012). Self-disclosing my ostomy to the dominant culture: An autoethnography. *Journal of Wound, Ostomy & Continence Nursing*, 39(6), 627-631.
doi:10.1097/WON.0b013e31826a4b83
- Frohlich, D.O. (2014). Support often outweighs stigma for people with inflammatory bowel disease. *Gastroenterology Nursing*, 37(2), 126-136.
doi:10.1097/SGA.0000000000000030
- Hanna, D. (2012). Roy's specific life values and the philosophical assumption of veritativity. *Nursing Science Quarterly*, 25(3), 245.
- Jasper, M. A. (1994), Issues in phenomenology for researchers of nursing. *Journal of Advanced Nursing*, 19, 309–314. doi: 10.1111/j.1365-2648.1994.tb01085.x
- Junkin, J., & Beitz, J. M. (2005). Sexuality and the person with a stoma: Implications for comprehensive WOC nursing practice. *Journal of Wound, Ostomy, and Continence*

- Nursing: Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN*, 32(2), 121-130. doi:10.1097/00152192-200503000-00009
- Kasperek, M. S. (2007). Long-term quality of life in patients with Crohn's disease and perianal fistulas: Influence of fecal diversion. *Diseases of the Colon & Rectum*, 50(12), 2067; 2067-2074; 2074.
- Knowles, S. R., Cook, S. I., & Tribbick, D. (2013). Relationship between health status, illness perceptions, coping strategies and psychological morbidity: A preliminary study with IBD stoma patients. *Journal of Crohn's & Colitis*, 7(10), e471-e478.
- Knowles, S. R., Wilson, J., Wilkinson, A., Connell, W., Salzberg, M., Castle, D., & Kamm, M. A. (2013). Psychological well-being and quality of life in Crohn's disease patients with an ostomy: A preliminary investigation. *Journal of Wound Ostomy & Continence Nursing*, 40(6), 623-629.
- Krouse, R., Grant, M., Ferrell, B., Dean, G., Nelson, R., & Chu, D. (2007). Quality of life outcomes in 599 cancer and non-cancer patients with colostomies. *Journal of Surgical Research*, 138, 79-87.
- Kubler-Ross, E., & Kessler, D (2005). On Grief and Grieving: Finding the meaning of grief through the five stages of loss. New York, Kubler-Ross, E. & Kessler, D (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. N.Y: Scribner.
- Kuruvilla, K., Osler, T., & Hyman, N. H. (2012). A comparison of the quality of life of ulcerative colitis patients after IPAA vs ileostomy. *Diseases of the Colon & Rectum*, 55, 1131-1137. doi:http://dx.doi.org/10.1097/DCR.0b013e3182690870
- Lee, R. M. (1998). The relationship between social connectedness and anxiety, self-esteem, and social identity. *Journal of Counseling Psychology*, 45(3), 338; 338-345; 345.

- Lefaiver, C. A., Keough, V., Letizia, M., & Lanuza, D. M. (2007). Using the Roy adaptation model to explore the dynamics of quality of life and the relationship between lung transplant candidates and their caregivers. *Advances in Nursing Science*, 30(3), 266-274.
- Levenstein, S., Li, Z., Almer, S., Barbosa, A., Marquis, P., Moser, G., & Drossman, D. A. (2001). Cross-cultural variation in disease-related concerns among patients with inflammatory bowel disease. *The American Journal of Gastroenterology*, 96(6), 1822-1830.
- LoBiondo-Wood, G., & Haber, J. (2013). *Nursing research in Canada: Methods, critical appraisal and utilization with study guide* (3rd ed.). Toronto: Mosby Elsevier.
- Notter, J., & Burnard, P. (2006). Preparing for loop ileostomy surgery: Women's accounts from a qualitative study. *International Journal of Nursing Studies*, 43(2), 147-159.
- Perry-Woodford, Z. (2013). Quality of life following ileoanal pouch failure. *British Journal of Nursing*, 22(15), S23-8.
- Pines, M. (1987). Shame-what psychoanalysis does and does not say. *Group Analysis*, 20(1), 16-31.
- O'Brien, B.K. (1999). Coming of age with an ostomy: Life with a stoma may be especially difficult for teens. *American Journal of Nursing*, 99(8), 71-75.
- Richbourg L., Thorpe J.M., & Rapp C.G. (2007). Difficulties experienced by the ostomate after hospital discharge. *Journal of Wound Ostomy Continence Nursing*, 34(1), 70-79.
- Roy, C. (1990). Response: Conceptual clarification. *Nursing Science Quarterly*, 3, 64-66.
- Roy, C. (2008). *The Roy adaptation model*. New Jersey: Pearson.
- Ryan, F., Coughlan, M., & Cronin, P. (2007). Step by-step guide to critiquing research. Part 2: Qualitative research. *British Journal of Nursing*, (16)12, 738-744.

- Sabil, F. (2011). *Crohn's disease and ulcerative colitis: Everything you need to know, the complete and practical guide*. New York, NY: Firefly Books
- Saunders, B. (2014). Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Sociology of Health & Illness*, 1-17. doi: 10.1111/1467-9566.12148
- Savard, J., & Woodgate, R. (2009). Young people's experience of living with ulcerative colitis and an ostomy. *Gastroenterology Nursing*, 32(1), 33-41.
doi:10.1097/SGA.0b013e3181965d40
- Schultz, K.F., Altman, D.G., & Moher, D., for the CONSORT Group. (2010). CONSORT 2010 statement: Updated guidelines for parallel group randomised trials. *British Medical Journal*, 340-c332. doi: 10.1136/bmj.c332
- Silva, M.A., Ratnayake, G., & Deen, K. (2003). Quality of life of stoma patients: Ileostomy versus colostomy. *World Journal of Surgery* 27, 421-424. doi:10.1007/s00268-002-669-4
- Simmons, K., Smith, J., Bobb, K., & Liles, L. (2007). Adjustment to colostomy: Stoma acceptance, stoma care self-efficacy and interpersonal relationships. *Journal of Advanced Nursing*, 60(6), 627-635. doi:10.1111/j.1365-2648.2007.04446.x
- Sinclair, L. G. (2009). Young adults with permanent ileostomies: Experiences during the first 4 years after surgery. *Journal of Wound, Ostomy, and Continence Nursing: Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN*, 36(3), 306-316. doi:10.1097/WON.0b013e3181a1a1c5
- Smart, L., & Wegner, D. M. (1999). Covering up what can't be seen: Concealable stigma and mental control. *Journal of Personality and Social Psychology*, 77(3), 474.
- Steinhart, H. (2006). *Crohn's & colitis: Understanding and managing IBD*.
Toronto, ON: Robert Rose, Inc.

- Storch, J.L., Rodney, P., & Starzomski R. (2013). *Toward a moral horizon: Nursing ethics for leadership and practice*. Toronto, ON: Pearson.
- Torraco, R. J. (2005). Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review*, 4(3), 356-367. doi:10.1177/1534484305278283
- Trachter, A. B., Rogers, A. I. & Leiblum, S. R. (2002). Inflammatory bowel disease in women: Impact on relationship and sexual health. *Inflammatory Bowel Diseases*, 8, 413–421.
doi: 10.1097/00054725-200211000-00006
- Walker, J. (2008). The Manitoba IBD cohort study: A population-based study of the prevalence of lifetime and 12-month anxiety and mood disorders. *The American Journal of Gastroenterology*, 103(8), 1989-1997.
- Wenger, E. (2011). Communities of practice: A brief introduction. *National Science Foundation*, (<https://scholarsbank.uoregon.edu/xmlui/handle/1794/11736>)
- World Health Organization (WHO). (2014). *Gender, women and health*. Retrieved from:
<http://www.who.int/gender/whatisgender/en/>
- Whitmore, R., & Knafelz, K., (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52 (5), 546–553

Title:			
Research questions: guidelines for critiquing a qualitative research study			
Elements influencing believability of the research			
Element	Questions	Comments	Score
Writing style	Is the report well written – concise, grammatically correct, avoids the use of Jargon? Is it well laid out and organized?		/1
Author	Do the researcher’s qualification/position indicate a degree of knowledge in this field?		/1
Report title	Is the title clear, accurate and unambiguous?		/1
Abstract	Does the abstract offer a clear overview of the study, including the research problem, sample, methodology, findings, and recommendations?		/1
Elements influencing robustness of the research			
Element	Questions	Comments	Score
Statement of the phenomenon of interest	Are the phenomenon of interest and the research question consistent? Is the phenomenon to be studied clearly identified?		/1
Study purpose	Is the purpose of the study/research problem clearly identified?		/1
Literature review	Has a literature review been undertaken? Does it meet the philosophical underpinnings of the study? Does the review of the literature fulfill its objectives?		/1
Theoretical framework	Has a conceptual or theoretical framework been identified? Is the framework adequately described? Is the framework appropriate?		/2
Methods and philosophical underpinnings	Has the philosophical approach been identified? Why was this approach chosen? Have the philosophical underpinnings of the approach been explained?		/1.5
Sample	Is the sampling method and sample size identified? Is the sampling method appropriate? Were the participants suitable for informing research?		/1.5

Title:			
Research questions: guidelines for critiquing a quantitative research study			
Elements influencing believability of the research			
Element	Questions	Comments	Score
Writing style	Is the report well written – concise, grammatically correct, avoids the use of jargon? Is it well laid out and organized?		/1
Author	Do the researcher's qualification/position indicate a degree of knowledge in this field?		/1
Report title	Is the title clear, accurate and unambiguous?		/1
Abstract	Does the abstract offer a clear overview of the study, including the research problem, sample, methodology, findings, and recommendations?		/1
Elements influencing robustness of the research			
Element	Questions	Comments	Score
Purpose/research problem	Is the purpose of the study/research problem clearly identified?		/1
Logical consistency	Does the report follow the steps of the research process in a logical manner? Do these steps naturally flow and are the links clear? Is the review logically organized?		/1
Literature review	Does it offer a balanced critical analysis of the literature? Is the majority of the literature of recent origin and mainly from primary sources and of an empirical nature?		/2
Theoretical framework	Has a conceptual or theoretical framework been identified? Is the framework adequately described? Is the framework appropriate?		/1
Aims/objectives/research question/hypotheses	Have aims, objectives, research question or hypotheses been identified? Have they been clearly stated? Do they reflect the information presented in the literature review?		/1
Sample	Has the target population been clearly identified? How were the sample selected? Was it probability or non-probability sample? Is it of adequate size? Are the inclusion/exclusion criteria clearly identified?		/1

QUALITATIVE RESEARCH STUDIES

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#1</p> <p>Frohlich, D. O. (2012)</p> <p>Self-disclosing my ostomy to the dominant culture: An autoethnography.</p> <p><i>Journal of Wound, Ostomy, and Continence Nursing: Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN</i>, 39(6), 627-631.</p> <p>Believability and Robustness Score: 18.75/20</p>	<p>Autoethnography</p> <p>Study Aim(s)</p> <p>A critical evaluation of the author's experiences of living with an ostomy and how the stoma affected his communication with others.</p> <p>Sample Population</p> <p>An adult male with ulcerative colitis who underwent colorectal surgery that resulted in a temporary ostomy. He was a university student at the time of surgery.</p> <p>Setting</p> <p>The environment of the author.</p>	<p>Data Collection: Orbe's co-cultural communication theory provided the framework for the research and was the lens for personal data collection. Data collected through quotes reflecting upon past experiences; experiences of communicating through social media and video blogging; and through the experiences of interacting with those without an ostomy.</p> <p>Data Analysis: Orbe identified three communication outcomes: Assimilation, accommodation and separation; and three communication approaches: Non-assertive, assertive and aggressive.</p> <p>Strengths: A richer understanding of life with an ostomy. Very clear linkage of theory and research. Orbe's theory an appropriate framework for the study. Limitations: Obvious small sample size and knowledge cannot be generalized. Recall validity, bias, possible censored information, data collection and strategies not a clearly defined and lacking in a systematic process.</p>	<p>No ethical considerations highlighted.</p>	<p>In this article. Self-disclosure to the dominant culture is a concern to those with ostomies. In Roy's model. The adaptive interdependence mode involves effective communication and having an adequate social support system (Roy, 2008).</p> <p>According to the author, people with ostomies belong to a co-cultural group. The role function mode focuses on social integrity, which involves knowing who one is in relation to others and how individuals' interact within society (Roy, 2008).</p>	<p>Findings:</p> <p>The author concluded that non-assertive assimilation, non-assertive accommodation and assertive accommodation were predominant in his personal communication.</p> <p>Implication for Nursing Practice</p> <p>Understanding how patients communicate and obtain information is important for health professionals. Self-disclosing their ostomies is a concern. Taking the time to allow patients to share their stories provides support and increases confidence towards sharing and disclosing with others.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#2</p> <p>Savard, J., & Woodgate, R. (2009). Young peoples' experience of living with ulcerative colitis and an ostomy. <i>Gastroenterology Nursing</i>, 32(1), 33-41. doi:10.1097/SGA.0b013e3181965d40</p> <p>Believability and Robustness Score: 18.75/20</p>	<p>Hermeneutic Phenomenology</p> <p>Study Aim(s)</p> <p>The aim of the study is to gain a deeper understanding of the lived experiences of young people living with IBD (specifically ulcerative colitis) and a temporary ostomy. With this new understanding and knowledge greater holistic nursing care can be provided to patients and families (p. 34).</p> <p>Sample Population</p> <p>6 young Caucasian adults ages 19 to 24 were included in the study. 5 female and 1 male all diagnosed with IBD and underwent a surgery for a temporary ostomy.</p> <p>Setting</p> <p>Recruitment took place at a tertiary care centre. Interviews were at a time and location convenient for the participant.</p>	<p>Data Collection: Between February and May 2007. Two audiotaped open-ended interviews lasting 30-150 min. An interview guide was developed. The first interview consisted of broad general questions. The second interview was an opportunity for the participant to expand on thoughts and for the interviewer to clarify information.</p> <p>Data Analysis: Started at the moment the participant began describing their experiences. Thematic statements were isolated by repeatedly reviewing the transcripts and by using the framework of Van Manen (1990).</p> <p>Strengths Rich descriptive narrative information has added to the qualitative literature on the IBD and ostomy experience.</p> <p>Limitations The retrospective design of the study can have limitations related to accurate memory recall. Having a balanced male female ratio may have returned different perspectives and uncovered more themes. Also this study did not include those with Crohn's disease and did not include those with permanent ostomies.</p>	<p>Permission to conduct the study was granted through the tertiary care centre where recruitment took place as well as from a university based ethics review board.</p> <p>There were no ethical considerations highlighted</p>	<p>The physiologic-physical mode: Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Allgood & Tomey, 2010). In this study, adaptation is hindered by the physical symptoms of the illness as well as from the unwanted side-effects of medications. The surgery provided relief from the physical pain which in turn helped towards adaptation.</p> <p>The self-concept mode. Self-concept is central to each individual. Meeting the needs of the physical and personal self are vital to positive adaptation (Roy, 2008). As described in the article, the altered body image and perceived stigma, restrictions in clothing all contributed to poor adaptation by having to conceal their true selves to others. Acceptance of having IBD, their life situation and knowing that the ostomy was temporary helped with adaptation.</p> <p>The role function mode Social adaptation is equally as important as physiological and psychological-spiritual adaptation (Roy, 2008). Stigma, embarrassment, the feeling of being different, frustration with the patient role all contribute to poor adaptation.</p>	<p>Findings: Concealing and revealing the self</p> <p>Theme 1: Uneasy feelings: Subthemes: embarrassment, feeling different, frustration worry, why me?</p> <p>Theme 2: It's hard: Subthemes: restrictions, unpredictability/loss of control, the pain.</p> <p>Theme 3: Renewed sense of self: Subthemes: freedom, new lease on life (p. 35).</p> <p>Implication for Nursing Practice</p> <p>The opportunity to express uneasy feelings in a safe empathetic environment. Nurses should be assessing the type and extent of social support that the patient has. Social support networks should be encouraged. Practitioners could arrange meetings with others of the same age who have undergone the same experience. Sense of self is affected and revealing themselves to others is stressful. Creating empathetic relationships allows for a safe environment for patients to share feelings (p.39).</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#3</p> <p>Sinclair, L. G. (2009).</p> <p>Young adults with permanent ileostomies: Experiences during the first 4 years after surgery.</p> <p><i>Journal of Wound, Ostomy, and Continence Nursing: Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN</i>, 36(3), 306-316. doi:10.1097/WON.0b013e3181a1a1c5</p> <p>Believability and Robustness Score: 19.25/20</p>	<p>Narrative Inquiry</p> <p>Clandinin and Connelly's Narrative knowing framework.</p> <p>Study Aim(s)</p> <p>"To understand the experiences of young adults living with a permanent ileostomy" (p. 306). To uncover meaning through narratives and to add to the knowledge base of nurses and those caring for patients with ostomies.</p> <p>Sample Population</p> <p>Purposeful sample of 7 participants: 4women and 3men. 4with UC, 2with CD and 1 with chronic constipation. The data obtained is relevant to the IBD population even though one of the participants was not an IBD patient.</p> <p>Setting</p> <p>Recruitment form colorectal surgery office and the United Ostomy Association.</p>	<p>Data Collection</p> <p>A single audiotaped interview was conducted with each participant lasting 1-2.5 hours. Conversation flow controlled the timeframe of the interview.</p> <p>Data Analysis</p> <p>Clandinin and Connelly's Narrative knowing framework was highlighted in the data analysis section.</p> <p>Strengths</p> <p>Rich narrative information was obtained which adds to the qualitative literature. Appropriate theoretical lens. Member checking to validate data. Author is an ET nurse.</p> <p>Limitations</p> <p>Caucasian sample only permanent ileostomies No detailed discussion surrounding the impact of IBD. Only one interview, a second may have shed more light and time for reflection of the participants.</p>	<p>Ethics was approved by both the University of Calgary and the Faculty of Medicine and the university's Faculty of Nursing. Confidentiality was assured.</p>	<p>The physiologic-physical mode:</p> <p>Pain and the physical struggles of the underlying disease prior to surgery had an impact on adaptation. Changes in elimination. Lack of education and written information hindered adaptation, self-education was addressed by five participants as important. Physical stoma complications and fear of complications hindered adaptation.</p> <p>The self-concept mode:</p> <p>All participants were shocked when they first saw their ostomies. One participant was comfortable managing the ostomy prior to discharge, the remaining six were "terrified". Positive attitude and empathic response from nurses helped with positive image and adaptation. Connecting with others who underwent the same procedure enhanced adjustment. Six felt ostomy affected their sex life. Psycho sexual education, addressing sexual concerns may help with adjustment. Lack of accurate information was the most significant deterrent to adjustment.</p> <p>The interdependence mode:</p> <p>Involves the interaction with others and relational integrity, the feeling of security within relationships (Roy, 2007). Single participants avoided dating. The three married participants appeared to be well supported and all had similar thoughts to how difficult this would be if single.</p>	<p>Findings:</p> <p>Common and divergent themes were identified. Shared common themes were associated with disease, hospital experiences, and personal and social adjustments (p. 309).</p> <p>Implication for Nursing Practice</p> <p>Cathartic effect of storytelling. Active listening, fosters trust, respect interpreting the meaning of silence, the grief response and recognition that the patient is suffering. Connecting with others who have undergone same procedure. Provide Empathetic and compassionate care. Negative experiences and interactions has long lasting impact and negatively affects adaptation. Nurses need to examine their own feelings when caring for those with an ostomy. Education: teaching should not be limited to WOC/ET nurses. Lack of accurate written information is a deterrent to positive adaptation. Psychosexual education to manage sexual and body image concerns (p. 313-314).</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#4</p> <p>Allison, M., Lindsay, J., Gould, D., & Kelly, D. (2013). Surgery in young adults with inflammatory bowel disease: A narrative account. <i>International Journal of Nursing Studies</i>, 50(11), 1566-1575. doi:10.1016/j.ijnurstu.2013.04.003</p> <p>Believability and Robustness Score: 18/20</p>	<p>Narrative approach</p> <p>Study Aim(s)</p> <p>To explore the experiences of young adults (18-25) who face or who have undergone surgery for inflammatory bowel disease.</p> <p>Sample Population</p> <p>24 participants: 13 women and 11 men. 7 with UC, 17 with CD. Of these: 11 white, Asian British, 5 Black British. 11 working, 9 in college or university, 4 with no occupation. 12 in a relationship and 12 single.</p> <p>Setting</p> <p>Adolescent and young adult clinic at a single tertiary care centre in the United Kingdom.</p>	<p>Data Collection</p> <p>One single interview was conducted with each participant and each interview transcribed verbatim. An interview schedule was created with open-ended questions capturing experiences before and after surgery.</p> <p>Data Analysis</p> <p>Two methods were used to organize data: Story mapping which provided a means of understanding changing themes through sharing past and present experiences and future intentions; and restorying to reduce and organize the data.</p> <p>Strengths</p> <p>Rich narrative information obtained which definitely adds to the qualitative literature related to IBD and the surgical experience. Large cohort for qualitative research balanced well between male and female.</p> <p>Limitations</p> <p>Single interviews may not have fully captured their experiences; a second interview may have provided greater participant reflection.</p>	<p>Ethical permission was granted by a local research ethics committee and local hospital research department. Support provided to those patients who experience distress in recalling thoughts and events.</p>	<p>The physiologic-physical mode: Trigger events such as worsening symptoms, complications, hospitalizations were indicators that surgery may be the only option. Nurturing parental support helped with physical recovery CD patients had concerns over disease recurrence.</p> <p>The role function mode: The patient role: Control and negotiation over surgery decisions were important. As is acknowledging feelings and concerns. Participants believed they were the experts on their condition. Emotional support from nursing was important (p. 1571).</p> <p>The self-concept mode: Change in body appearance associated with having a scar and stoma affected both men and women. However the stoma affected women more in terms of sexuality, desirable to Actual/potential partners. Being treated the same as healthy peers helped with adaptation.</p> <p>The interdependence mode: If the stoma was temporary many limited their lifestyle and waited until reversal. Adaptation was gradual; being able to see the positive changes that the stoma had brought helped in adaptation. Disclosing the ostomy to others was a concern but acceptance of the stoma came much easier than anticipated. Friendships were important. Women: Sought comfort and support from their partners. Men: Wanted practical help. Permanent ostomy patients had better adaptation than those with temporary ostomies.</p>	<p>Findings:</p> <p>Key themes: Perception of surgery, self, support and coping strategies (p.1569).</p> <p>Implication for Nursing Practice:</p> <p>Emotional support and continuity of care from nursing was important. Feelings opinions and concerns need to be acknowledged and patients should be included in the decision making process. Factors that contributed to positive adaptation are recognizing how surgery could change life in a positive way, having a positive attitude and active information seeking.</p> <p>Information seeking: from health care professionals, the internet and from other patients who had the surgery. Important for healthcare professionals to be aware of the resources and help those to access reliable information.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#5</p> <p>Notter, J., & Burnard, P. (2006).</p> <p>Preparing for loop ileostomy surgery: Women's accounts from a qualitative study.</p> <p><i>International Journal of Nursing Studies</i>, 43(2), 147-159.</p> <p>Believability and Robustness Score: 19/20</p>	<p>Descriptive phenomenology</p> <p>Study Aim(s)</p> <p>To explore the experiences of women and their preparation and experiences of a loop ileostomy.</p> <p>Sample Population</p> <p>Purposive sample of 50 women most with UC recruited over 3 years.</p> <p>Setting</p> <p>Unknown.</p>	<p>Data Collection</p> <p>Semi structured interviews were conducted with each participant and were recorded and transcribed.</p> <p>Data Analysis</p> <p>Steps in analysis were clearly identified and described. Findings were analysed following the rigorous principles of descriptive phenomenology. (Each transcript was described and explored for meaning. Each were re-described to clarify the experience shared. Researchers commented on the importance of bracketing.</p> <p>Strengths: were not mentioned in the study. However the findings were very rich in detail, supported by subject quotes. A very large cohort for a phenomenological study that spanned over 3 years.</p> <p>Limitations: Findings cannot be applied to the population as a whole; a single interview can be limiting in terms of sharing of experiences. Memory recall.</p>	<p>No mention in the article of how ethics approval was obtained or whether the participants were informed about the nature of the research. The setting was also not described.</p>	<p>The physiologic-physical mode: All subjects reported that pain dominated their memories. Adequate analgesia while in hospital is imperative for comfort and towards the process of adaptation. Debilitating and prolonged weakness and fatigue persisted for some over a year. Leaking bags, smell was repulsive for some.</p> <p>The role function mode: Relationship development between nurse and patient based on mutuality, in accepting the others role. Recognizing sensitive issues, to be a participatory member and to have all the information needed and at the right time to make informed decisions. Wanting of adequate written information</p> <p>The self-concept mode: The shock of seeing the stoma for the first time, memories still as vivid as years before. Proper education and counselling prior could be beneficial. Few had any idea what an ileostomy looked like until after surgery, this contributed to difficulties in accepting the stoma. Body image and sexuality was altered. The shock of family members did not help with positive coping. "Who would still want me" (p.152).</p> <p>The interdependence mode: Concerns over husband's negative thoughts of the stoma, feeling not the same and less of a woman inhibited adaptation. A supportive and caring partner helped with positive coping. Pre and post-operative counseling could benefit.</p>	<p>Findings:</p> <p>Themes: "pain and shock, body image and sexuality, the loop ileostomy itself and the roles of the general and specialist nurses" (p. 151).</p> <p>Implication for Nursing Practice</p> <p>Psychosocial support before and after surgery for patient partners and family members. Adequate information in preparation for what to expect. Impact of the immediate postoperative period was profound. Encourage to discuss feelings and provide information on task mastery and coping.</p> <p>Nursing staff as well as community nurses should be properly trained and feel confident in caring for the ostomized patient. Not just the physicality of stoma care but the psychosocial as well.</p> <p>Specialist nurses need to be involved in educating staff nurses.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#6</p> <p>Perry-Woodford, Z. (2013).</p> <p>Quality of life following ileoanal pouch failure.</p> <p><i>British Journal of Nursing</i>, 22(15), S23-S28.</p> <p>Believability and Robustness Score: 19.5/20</p>	<p>Interpretive phenomenological analysis (IPA)</p> <p>Study Aim(s)</p> <p>To explore the lived experiences of patients with ileo-anal pouch failure.</p> <p>Sample Population</p> <p>Yes, purposive sample of 3 women and 3 men.</p> <p>Setting</p> <p>All participants were interviewed in the counselling room of St Mark's Hospital in the UK.</p>	<p>Data Collection</p> <p>Semi structured face-to-face interviews were conducted with each participant and were recorded and transcribed verbatim.</p> <p>Data Analysis</p> <p>The six steps in IPA analysis were clearly identified and described.</p> <p>Strengths: Rich narrative information obtained which definitely adds to the qualitative literature related to pouch failure in those with ulcerative colitis.</p> <p>Limitations: Single interviews may not have fully captured their experiences. A second interview may have provided greater participant reflection. The participants knew the author and this may have had an impact on participant sharing.</p>	<p>Ethics approval from the NHS research ethics committee and the Research and the Development department at St Mark's Hospital.</p>	<p>The physiologic-physical mode: Impact on activities of daily living, incontinence, physical regression towards symptoms of ulcerative colitis.</p> <p>The interdependence mode: Maintaining personal relationships. Vital to maintain working and personal relationships. Dealing with the perceived loss helps with regaining social function.</p>	<p>Themes: Managing expectations; feelings of loss; information discontinuum; maintaining personal relationships; merging timelines (p. s24).</p> <p>Implications for practice: Information needs vary, it's important to tailor information accordingly.</p> <p>Information discontinuum was clearly an issue in adaptation.. Developing a pathway document explaining the stages of surgery and the risks and benefits, so patients are clearly informed and better prepared would assist in adaptation (p.s27).</p> <p>Difficulty in absorbing large amounts of information when unwell. Education practices should accommodate for this (p. s28).</p> <p>Support should be extended to the family as they are often the "pillar" during this time of failure and transition to ileostomy (p. s28). Developing social links and support groups assist in decreasing isolation and improve adaptation.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical factors	Roy's Adaption Model (RAM)	Findings & Implication for Nursing Practice
<p>#7</p> <p>Frohlich, D., Owen. (2014).</p> <p>Support often outweighs stigma for people with inflammatory bowel disease.</p> <p><i>Gastroenterology Nursing, 37(2), 126-136.</i> doi:10.1097/SGA.000000000000030</p> <p>Believability and Robustness Score: 19.25/20</p>	<p>Phenomenology</p> <p>Study Aim(s)</p> <p>To understand how people with IBD experience stigma during their disease.</p> <p>Sample Population</p> <p>14 participants: 7 women and 7 men. 7 with Crohn's disease and 7 with ulcerative colitis. 5 were living with permanent ostomies, and four had ostomies in the past.</p> <p>Setting</p> <p>Recruitment through Facebook support groups. Recruitment messages were posted inviting those interested to contact the author by email it set up an interview.</p>	<p>Data Collection</p> <p>Interviews were conducted through Skype. Participants were asked to share their IBD story, allowing them to ground the interview in their experience (p 128). This narrative became the basis for further questions.</p> <p>Data Analysis</p> <p>Interviews were transcribed verbatim, read and reread to identify themes.</p> <p>Strengths: Rich narrative information obtained which definitely adds to the qualitative IBD literature surrounding stigma.</p> <p>Direct quotes from subjects were shared which added to the richness and credibility. Validity and reliability were discussed.</p> <p>Limitations: Possible researcher bias and reactivity since the author has IBD.</p>	<p>Ethics approval from the university ethics board of the author's university.</p> <p>Recruitment through Facebook support groups.</p>	<p>The physiologic-physical mode: Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Alligood & Tomey, 2010). Ostomy was not an ideal situation, but was better than living with uncontrollable IBD (p. 132). How to manage the ostomy. Internet support was a great help for many participants.</p> <p>The role function mode: Social adaptation is equally as important as physiological and psychological-spiritual adaptation (Roy, 2008). The role of a patient and the interactions with healthcare professionals such as dismissing, being <i>overly dramatic</i>, not comforting can have a profound impact on stigma.</p> <p>The self-concept mode: is central to each individual; meeting the needs of the physical and personal self are vital to positive adaptation (Roy, 2008).</p> <p>The interdependence mode: Involves the interaction with others and relational integrity, the feeling of security within relationships. (Roy, 2007). Many participants feared how their partners would accept the ostomy. None reported any negative feelings coming from their romantic partners. Support from family and friends is paramount.</p>	<p>Themes: Initial diagnosis, romantic relationships, work and school, surgery, medicine, overt stigma.</p> <p>The support people received far outweighed the stigma people experienced.</p> <p>Disease difficult to manage but the ostomy gave a new lease on life.</p> <p>Implications for Nursing Practice</p> <p>Managing IBD is more than symptoms pills and diet. It affects relationships: recommend support resources, websites, support groups (p135).</p> <p>Don't manage in isolation: ask how patients are managing socially not just in terms of their body (p135)</p> <p>"When patients are stigmatized by the healthcare profession this experience can be long lasting. Be sympathetic, if a patient doesn't look sick it doesn't mean they aren't sick trust in them and don't doubt how the disease is making them feel" (p. 135).</p>

APPENDIX D: LIVING WITH IBD AND AN OSTOMY

QUANTITATIVE RESEARCH STUDIES

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#8</p> <p>Carlsson, E., Bosaeus, I., & Nordgren, S. (2003).</p> <p>What concerns subjects with inflammatory bowel disease and an ileostomy?</p> <p><i>Scandinavian Journal of Gastroenterology</i>, 38, 978-984.</p> <p>Believability and Robustness Score: 18/20</p>	<p>Questionnaire Survey</p> <p>Study Aim(s)</p> <p>To describe worries and concerns of IBD patients with an ileostomy and to describe quality of life and coping strategies.</p> <p>Sample Population</p> <p>21 subjects with IBD and an ileostomy; probability sampling; inclusion/exclusion criteria clearly defined. Matched controls from the general population.</p> <p>Setting</p> <p>Subjects recruited from the Goteborg area of Sweden.</p>	<p>Data Collection: Rating Form of IBD Patient Concerns (RFIPC) to assess worries and concerns. SF-36 was used to assess Health Related Quality of Life (HRQOL). Jalowiec coping scale (JCS 40) was used to assess coping strategies. Perceived quality of life, general health and health concerning bowel habits: 3 questions with VAS 0-100 response.</p> <p>Data Analysis- due to the limited sample size the evaluation is mainly descriptive (p. 980). The ordinal data of RFIPC does not follow a normal distribution: Median and IQR were preferred. SF-36 values and comparisons CI: 95% and P value <0.05 was considered significant. JCS-40 sum score mean for questions and 3 independent coping dimensions.</p> <p>Strengths: 4 tools used to assess and describe research question. Long-term experiences shared. The recommendation of the RFIPC in clinical practice to assist in recognition of concerns. Perceived quality of life, general health and health concerning bowel habits-positive and negative attributes shared.</p> <p>Limitations: Small cohort of patients, permanent ileostomies only.</p>	<p>Ethics committee approval from the medical faculty of the University of Goteborg.</p> <p>Informed consent was obtained from participants.</p>	<p>The physiologic-physical mode: Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Allgood & Tomey, 2010). Patients' experiences of lower energy levels and vitality can disrupt adaptation.</p> <p>The role function mode: focuses on social integrity, which involves knowing who one is in relation to others and how individuals' interact within society (Roy, 2008). Feeling like a burden on others can influence adaptation.</p> <p>The self-concept mode: The physical self focuses on body image and bodily sensations; the personal self emphasizes self-ideal (Allgood & Tomey, 2010; Roy, 2008). Feeling unattractive, unpleasant odours, poor body image. Confrontational coping helps with adaptation by maintaining a sense of control over the situation. Sexuality, intimacy, sexual performance was affected.</p>	<p>Findings</p> <p>RFIPC- Intimacy, accessible medical care, energy level, loss of sex drive, unpleasant odours, burden, sexual performance, attractiveness, body image (p.980)</p> <p>SF-36- Lower vitality.</p> <p>JCS 40 – Coping - maintain control Confrontational</p> <p>Implication to Nursing Practice</p> <p>Intimacy and sexual concerns are areas that needs to be focussed on pre and post operatively. Possibly using the RFIPC in clinical practice may be a useful tool in addressing individual needs and concerns. Counselling education and intervention.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#9</p> <p>Knowles, S. R., Cook, S. I., & Tribbick, D. (2013).</p> <p>Relationship between health status, illness perceptions, coping strategies and psychological morbidity: A preliminary study with IBD stoma patients.</p> <p><i>Journal of Crohn's & Colitis</i>, 7(10), e471-e478.</p> <p>Believability and Robustness Score: 19/20</p>	<p>Online questionnaire Survey</p> <p>Study Aim(s)</p> <p>In a cohort of 83 patients with IBD the CSM was used to explore interrelationships between illness perceptions, health status, coping strategies anxiety and depression were to be highlighted (p. 476)</p> <p>Sample Population</p> <p>Moderate size of 83 exclusively IBD adults with a stoma. 23 males, 60 female. Inclusion/exclusion criteria clearly defined. Probability sample</p> <p>Setting</p> <p>Online survey</p>	<p>Data Collection: Online questionnaire survey, 4 data collecting instruments clearly defined and appropriate for use. Health Status Subscale (HSS), Brief Illness Perception Questionnaire (BIPQ), Carver brief coping questionnaire (Brief-COPE), Hospital Anxiety and Depression Scale (HADS). no pilot study undertaken.</p> <p>Data Analysis:</p> <p>All questionnaires were assessed using Cronbach's alpha (test of internal consistency).</p> <p>Strengths</p> <p>A valid model and well published measures.</p> <p>Limitations</p> <p>No QOL measured, IBD severity was not measured directly, 72% female, based on self-report, social support and self-care were not included.</p>	<p>Ethics committee approval from Swinburne University of Technology Human Ethics Research Committee.</p>	<p>The physiologic-physical mode: Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Allgood & Tomey, 2010). The psychological conditions of depression and anxiety can have a physiological affect and hinder adaptation.</p> <p>The self-concept mode: The physical self focuses on body image and bodily sensations; the personal self emphasizes self-ideal (Allgood & Tomey, 2010; Roy, 2008). Having IBD and a stoma was associated with psychological distress. The psychological conditions of depression and anxiety can have an effect on self-concept and hinder adaptation.</p>	<p>Findings:</p> <p>Health status had an adverse influence on illness perception and in turn an influence on maladaptive coping. The more recent the surgery the more maladaptive coping (p.475). The further time from surgery the better emotion focussed coping strategies were adopted.</p> <p>Implication to Nursing Practice</p> <p>Nurses should be aware of the increased risk for anxiety and depression in this population. And how health status influences illness perceptions and in turn influenced coping. This can negatively impact adaptation especially in the early postoperative stages.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#10</p> <p>Krouse, R., Grant, M., Ferrell, B., Dean, G., Nelson, R., & Chu, D. (2007).</p> <p>Quality of life outcomes in 599 cancer and non-cancer patients with colostomies.</p> <p><i>Journal of Surgical Research, 138, 79-87.</i></p> <p>Believability and Robustness Score: 19.5/20</p>	<p>Comparative description: Questionnaire.</p> <p>Study Aim(s): 1) To identify common QOL concerns of patients with colostomies; 2) to compare QOL concerns of patients with and without cancer who have colostomies; 3) to analyze differences adjusting for demographics characteristics and time since colostomy (p. 80).</p> <p>Sample Population: Large sample size of 599 adult permanent colostomy patients. 517 with cancer (254 M, 263 F) and 82 without cancer (20 M, 62 F). 33: IBD.</p> <p>Setting The questionnaire was sent to all members of the California United Ostomy Association.</p>	<p>Data Collection: The City of Hope QOL-Ostomy Questionnaire was used to measure QOL, demographic and personal data. Questionnaire has two sections: First 46 descriptive questions, the second is composed of 43 items divided into the four dimensions. Items are scaled: 0 to 10, with 0 being the worst QOL and 10 the best (p. 80).</p> <p>Data Analysis-Overall the scores are computed by adding scores in each subscale and dividing by the number of items. All questionnaires were assessed using the JMP Statistical Discovery Software, version 4.0. Univariate logistic regression methods were performed using the Pearson's Chi square statistic of QOL measures.</p> <p>Strengths: Large cohort, detailed descriptive components. Strong survey design. Limitations: Small percentage of IBD patients. Age range for IBD patients was between: 15-92, 76% female. Having a clearer picture of the ages of those who participated can be significant in terms of the difference in age associate with adaptation. 95% Caucasian. Exclusion of ileostomy surgeries removes another dimension of IBD ostomy patients.</p>	<p>Ethics approval from the institutional review board with receipt of mailed surveys as informed consent.</p>	<p>The physiologic-physical mode: Persistent aches, pain, fatigue, strength, sleep disruptions; skin irritations are more prevalent in those with non-cancer (IBD). Those with non-cancer IBD this may be reflective of continued disease exacerbations.</p> <p>The role function mode: Feeling useful more of an impact.</p> <p>The self-concept mode: Body image was more affected in IBD group (Age and gender I believe may play a role in this as 76% non-cancer respondents were female) Spiritually: positive changes not as evident in the IBD group. Anxiety and depression more prevalent in benign group. Sexuality impacted.</p> <p>The interdependence mode: Personal relationships, sexuality and social support systems were affected. Group and individual discussions were found to be helpful. Counselling could be of benefit. Despite the long time for adjustment (8 years for those with non-cancer diagnosis) there were persistent problems across all QOL dimensions.</p>	<p>Findings</p> <p>Overall cancer patients had less difficulty adjusting to their colostomies (p. 79).</p> <p>Implication to Nursing Practice</p> <p>Worry and concern over disease recurrence is common for those with CD. These worries can impact QOL and hinder adaptation. These concerns need to be addressed.</p> <p>Pre and post-operative teaching and counselling patients with stomas should be tailored individually to meet the needs and concerns of the relative age group.</p> <p>Multifactorial issues contributing to decrease sexual and intimacy relations. These need to be addressed in order for successful adaptation to ensue.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#11</p> <p>Kasperek, M. S., Glatzle, J., Temeltcheva, T., Mueller, H., Koenigsrainer, A., & Kreis. (2007).</p> <p>Long-term quality of life in patients with Crohn's disease and perianal fistulas: Influence of fecal diversion.</p> <p><i>Diseases of the Colon & Rectum</i>, 50(12), 2067; 2067-2074; 2074.</p> <p>Believability and Robustness Score: 18.75/20</p>	<p>Questionnaire with four quality of life instruments</p> <p>Study Aim(s): To compare long-term quality of life in patients with Crohn's disease with symptomatic perianal fistulas who were treated with or without fecal diversion (p. 2067)</p> <p>Sample Population: 77 patients (55 F and 22) completed the questionnaire. 30 did not</p> <p>Inclusion/exclusion criteria not clearly defined.</p> <p>Setting</p> <p>Computerized patient registry at the department of General surgery, University of Tuebingen. Questionnaires were sent to potential participants.</p>	<p>Data Collection: A custom-made questionnaire was sent to each participant capturing history, complaints related to disease activity and medications. 4 QOL instruments were used: the short-form general health survey (SF-36); the gastrointestinal QOL index (GIQLI); the Cleveland global score (CGQL); and the short inflammatory bowel disease questionnaire (SIBDQ). All validated questionnaires. (p. 2068).</p> <p>Data Analysis-Patients were divided into 2 groups: With and without fecal diversion. Characteristics were captured as ranges. The QOL questionnaires are given as the scores of the different subscales. Component summaries are given as percentages means and standard deviations. Mann-Whitney rank sum tests, chi-squared test, or ANOVA were used when appropriate. P<0.05 (p. 2069).</p> <p>Strengths: Validated questionnaire used</p> <p>Limitations: No longitudinal assessment of QOL. Patients with a diversion had been suffering a long time and the experience of the stoma was a relief potentiating the report of QOL. Some questions not designed for stoma patients; results may have been compromised.</p>	<p>Ethics committee approval from the University of Tuebinge, Germany, and Each patient provided written informed consent.</p>	<p>The physiologic-physical mode:</p> <p>Physiologic integrity is a basic need and adaptation is contingent upon how a person responds to both the internal and external environments (Alligood & Tomey, 2010). The relief of bothersome gastrointestinal symptoms is relieved with the institution of a fecal diversions. Adaptation can be improved with the relief of severe symptoms.</p> <p>The interdependence mode & The self-concept mode:</p> <p>Because of the stoma avoidance of activities such as sports, sex, swimming was captured by five patients (p. 2072). This disruption interferes with positive adaptation.</p>	<p>Findings</p> <p>SF-36: No difference.</p> <p>GIQLI: QOL better in diverted patients in terms of GI symptoms and overall score.</p> <p>CGQL: No difference.</p> <p>SIBDQ: QOL better in terms of bowel function.</p> <p>Implication to Nursing Practice</p> <p>Relay how a stoma can bring improved QOL with the relief of symptoms associated with severe perianal CD. Developing and an individualized plan with successful coping strategies can be suggested in order to help with positive adaptation.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#12</p> <p>Camilleri-Brennan, J., Munro, A., & Steele, R. J. (2003).</p> <p>Does an ileoanal pouch offer a better quality of life than a permanent ileostomy for patients with ulcerative colitis?</p> <p><i>Journal of Gastrointestinal Surgery</i>, 7, 814-819.</p> <p>Believability and Robustness Score: 18.75/20</p>	<p>A matched pair comparative study.</p> <p>Study Aim(s):</p> <p>Ileoanal pouch procedure is frequently offered to patients with ulcerative colitis, but it's not clear to what degree this procedure is advantageous over an ileostomy. Do patients with a pouch have less morbidity and between QOL than those with a permanent ileostomy?</p> <p>Sample Population:</p> <p>Patients were referred by 2 teaching hospitals. 19 patients who had undergone pouch formation were matched with 19 patients who had a permanent ileostomy. Probability sample.</p> <p>Setting</p> <p>Hospital, Scotland.</p>	<p>Data Collection:</p> <p>A matched pair comparative study using the validated: IBDQ and SF-36 II. Also a few extra questions on body image were included in the collection. Potential participants were contacted by mail and by telephone and invited to participate. 19 pouch procedure patients were matched with 19 ileostomy for disease process, time since surgery, sex, age, and socioeconomic status (p. 816).</p> <p>Data Analysis-</p> <p>Nonparametric tests were used as the scores were not normally distributed. Differences were compared using the Wilcoxon signed rank. QOL scores were conveyed as standardized median scores and interquartile ranges (p. 815).</p> <p>Strengths: Validated questionnaires used.</p> <p>Limitations: Small sample size. A larger sample size would permit further statistical analysis. In most cases the patients chose the procedure that they felt was best for them, this could introduce bias. The questions on body image were not validated, and the questionnaires were not designed for stoma patients.</p>	<p>Approval by the Tayside Committee on Medical Research Ethics and the Highland Health Board Ethics Committee.</p> <p>Informed consent obtained.</p>	<p>The physiologic-physical mode: Elimination of ulcerative colitis and the burden of these symptoms rather than the procedure itself contributes to improved QOL.</p> <p>The self-concept mode: Perception of body image was better in those with a pouch over those with an ostomy.</p>	<p>Findings: Short term: ileostomy patients had more complications associated primarily with the perineal wound. Long term: patients with the pouch had more problems associated with pouchitis. Another disadvantage: the number of staged operations. Generally the QOL in both groups were similar. Body image was better in the pouch group. Body image did not necessarily correlate with better QOL. Most likely the elimination of the disease not the procedure is what contributes to improve QOL (p. 818).</p> <p>Implication to Nursing Practice</p> <p>Discussing both surgical options, the stages and potential complications with patients prior to surgery. Patients need to be well supported and informed on what to expect in order to successfully adapt to the challenges ahead. Individual approach to care.</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p>#13</p> <p>Kuruville, K., Osler, T., & Hyman, N. H. (2012).</p> <p>A comparison of the quality of life of ulcerative colitis patients after IPAA vs ileostomy.</p> <p><i>Diseases of the Colon & Rectum</i>, 55, 1131-1137. doi:http://dx.doi.org/10.1097/DCR.0b013e3182690870</p> <p>Believability and Robustness Score: 18.5/20</p>	<p>A cross-sectional, observational study.</p> <p>Study Aim(s):</p> <p>To perform a comprehensive assessment of HRQOL post colectomy and to see how long-term QOL compares between those patients with a pelvic pouch and those with a permanent ostomy.</p> <p>Sample Population:</p> <p>Ileal pouch anal anastomosis IPAA patients: (35) and those with an Ileostomy: (24)</p> <p>Setting</p> <p>Fletcher Allen Health Care, Burlington Vermont</p>	<p>Data Collection:</p> <p>the following 5 validated questionnaire used were utilized:</p> <p>EQ-5D-3L: non-disease specific HRQOL questionnaire.</p> <p>SIBDQ: IBD on daily functioning.</p> <p>CGQL: QOL after IPAA (can be used for other indications).</p> <p>Fecal Incontinence Quality of Life Scale: HRQOL.</p> <p>Stoma Quality of Life Scale: Work, /social, stoma function and sexuality/body image.</p> <p>Data Analysis:-</p> <p>Statistics: means, standard deviations for continuous variable and frequencies for qualitative variables (p 1133). For differences in QOL the Mann-Whitney U test.</p> <p>Strengths: Validated questionnaire used</p> <p>Limitations: Small sample size, same surgeon performed procedure limiting generalizability, no baseline disease severity or QOL measured prior to surgery.</p>	<p>Ethics approval granted by The University of Vermont IRB.</p>	<p>The self-concept mode:</p> <p>The physical self focuses on body image and bodily sensations; the personal self emphasizes self-ideal (Allgood & Tomey, 2010; Roy, 2008).</p> <p>Issues surrounding body image need to be addressed.</p> <p>The interdependence mode:</p> <p>Refers to the value of close relationships, the ability to give and receive respect, value and love. It involves effective communication and having an adequate social support system (Roy, 2008).</p> <p>Issues surrounding sexuality and social functioning are apparent with those living with an ostomy. Addressing these concerns can assist in promoting adaptation.</p> <p>The role function mode: focuses on social integrity, which involves knowing who one is in relation to others and how individuals' interact within society (Roy, 2008).</p> <p>Work functioning was negatively impacted by the ostomy.</p>	<p>Findings:</p> <p>IPAA and ileostomy patients share similar global HRQOL however there are better outcomes for IPAA patients related to sexuality, body image work and social functions as well as skin irritation.</p> <p>Implication to Nursing Practice</p> <p>Sexuality, body image, work and social functioning need to be followed more closely in those with an ileostomy. Perhaps closer nursing follow up should be offered as it appears that they are only being seen on an add need basis. Annual evaluation. Only offered annual follow up in the absence of stoma related problems" (p. 1132).</p>

Citation	Description of the Methodology	Research Methods & Strengths/Limitations	Ethical Factors	Roy's Adaption Model (RAM)	Findings & Implication to Nursing Practice
<p># 14</p> <p>Knowles, S. R., Wilson, J., Wilkinson, A., Connell, W., Salzberg, M., Castle, D., Kamm, M. A. (2013).</p> <p>Psychological well-being and quality of life in Crohn's disease patients with an ostomy: A preliminary investigation.</p> <p><i>Journal of Wound Ostomy & Continence Nursing</i>, 40(6), 623-629.</p> <p>Believability and Robustness Score: 19/20</p>	<p>Questionnaire Descriptive cross sectional design.</p> <p>Study Aim(s): To explore psychological concerns, psychiatric symptoms, timing and type of surgery (temporary vs permanent); anxiety, depression, and HRQOL in people with Crohn's disease. Also the extent and use of past or current psychological care and psychotropic medication.</p> <p>Sample Population: 80 participants identified 31 patients (14 women and 17 men) with CD and an ostomy.</p> <p>Setting recruited from 2 teaching hospitals in Melbourne, Australia. They were contacted and mailed the study questionnaire.</p>	<p>Data Collection: Three validated questionnaire used were used.</p> <p>Brief Illness Perceptions Questionnaire: Measures illness perceptions on five dimensions: consequence, timeline, identity, cause and cure or control.</p> <p>The Hospital Anxiety and Depression Scale(HADS):14 item self-report instrument that evaluates depression and anxiety over the previous week</p> <p>Stoma Quality of Life Scale (SQOL): A 21 item self-report questionnaire with five dimensions: Work/social function, skin irritation, stoma function, financial concerns and sexuality/body image.</p> <p>Three open ended questions</p> <p>Data Analysis-: Predictive Analytics Software. Continuous variables were presented as means with SD. Analysis between groups used the Mann-Whitney U test. P Value<0.05 was deemed statistically significant.</p> <p>Strengths: Validated questionnaire used</p> <p>Limitations: Low response rate of 39%. Unsure how representative this data is. There was no comparison to IBD without a stoma or the general population.</p>	<p>Ethics approval granted by St Vincent's hospital Human research ethics Committee.</p>	<p>The self-concept mode:</p> <p>The physical self focuses on body image and bodily sensations; the personal self emphasizes self-ideal (Alligood & Tomey, 2010; Roy, 2008). Struggles with anxiety, depression sexuality and body image are evident with CD and an ostomy and can impact psychological function and adaptation.</p> <p>The physiologic-physical mode:</p> <p>Ongoing problems with stoma and stoma function: skin irritation, noise, smell.</p>	<p>Findings: Gender, timing or type of surgery was not significantly associated with HRQOL, anxiety or depression (p. 623).Higher illness beliefs in temporary vs permanent. Poor illness perception was significantly correlated with increased anxiety, depression and reduced HRQOL (Sexuality and body image, work and social functioning ad financial concerns)</p> <p>Three open ended questions: Seven out of 12 reported improved HRQOL, eight out of 12 described ongoing problems.</p> <p>Implication to Nursing Practice Identify patients who are struggling with anxiety and depression. Sexuality and body image impacts on HRQOL this needs to be approached. Temporary stoma patients have higher illness beliefs impacts on HRQOL.</p> <p>Teaching: A poorer understanding of their illness showed higher depression and lower HRQOL.</p>