

Running Head: ANP IN NURSE-LED IBD SUPPORT SERVICE

Advanced Nursing Practice in Nurse-Led
Inflammatory Bowel Disease Support Service

By

Lisa Westin
BSN, University of Victoria, 2001

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Supervisory Committee
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Supervisory Committee

Dr. Laurene Sheilds (School of Nursing)
Associate Professor, Associate Dean - Academic, Supervisor

Dr. Noreen Frisch (School of Nursing)
Professor, Director, Committee Member

Dr. Su-Er Guo (School of Nursing)
Assistant Professor, Chair, External Examiner

Supervisory Committee

Dr. Laurene Sheilds (School of Nursing)
Associate Professor, Associate Dean - Academic, Supervisor

Dr. Noreen Frisch (School of Nursing)
Professor, Director, Committee Member

Dr. Su-Er Guo (School of Nursing)
Assistant Professor, Chair, External Examiner

Abstract

This project examines the experiences of patients who have inflammatory bowel disease (IBD) through an integrative literature review. The human science approach of phenomenology and Watson's Caring Theory (2006) serve as the philosophical and theoretical perspectives of this project and are integrated into a framework for ANP within the context of IBD. The framework is further supported by an examination of best practices in nurse-led support programs with an emphasis on chronic disease. My ultimate goal in developing this ANP framework in an IBD support program was to establish the scope and parameters of my ANP role and to incorporate best practices that will positively impact the patients' experiences of illness, healing, and health.

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Chapter 1 - Project Foundation

Introduction

The human experiences of health and illness occur every day in my personal and professional life and in the lives of the patient population I have engaged with in my practice. People who live with inflammatory bowel disease (IBD) are the focus of my practice and I have developed this project to gain further appreciation for, and understanding of, the meaning of their lived experiences while facing this debilitating disease.

As I broaden my understanding of the experiences of people living with IBD, a human science perspective of phenomenology and caring theory guides my practice. In addition, my nursing practice has evolved to encompass the competencies of Advanced Nursing Practice (ANP), (Canadian Nurses Association [CNA], 2008). In order to achieve the distinction of ANP working with the IBD population, I intend to establish a framework of practice that integrates the theoretical and philosophical perspectives that serve as the foundation for my nursing practice.

The patients I meet in my practice may have just learned they have IBD or have lived with the disease for a number of years. The salient aspects of their experiences of health and illness can be similar, but the meaning each person attaches to those experiences is unique. My role as Case Manager for Gastroenterology (GI) allows me to assist each patient as they manage their illness experience and work toward achieving optimal health. My experiences in working with this population have led me toward a personal and professional interest in understanding their lived experiences and in developing an ANP role that positively impacts their quality of life and helps them to achieve and maintain a sense of well-being.

Although I had already established my role as Case Manager for Gastroenterology in my practice setting, I believed that the role would be enhanced and more effective in improving

health outcomes and quality of life for the IBD population by developing a distinct ANP framework. This framework is developed from the knowledge I have gained through an integrative literature review in conjunction with an examination of the roles, best practices and the design of ANP programs. This framework is also reflective of the theoretical and philosophical approaches I have embraced as the foundation of my nursing practice. I believe that the framework will be well founded through my practical knowledge of the lived experiences of the IBD population, identifying aspects of best practices in nursing, and articulating ANP competencies that I have incorporated during the evolution of my role as Case Manager. The timing of implementing an ANP framework for my role is an important consideration as my position is situated within the context of health system reform.

Canada's national and provincial health systems are evolving as demands for health services are increasing and resources are stretched. Access to quality health services and patient-focused care in a sustainable, efficient and effective health system are key priorities in the Alberta government health service model (Alberta Health and Wellness, 2008). ANP is taking the forefront in health system reform during this transition and is being recognized for its value and impact on quality health care, the health outcomes of patient populations, and the integration of safe, efficient and effective health resources. Now, more than ever, it is crucial to distinctly identify the advantages of ANP roles in improving access and quality of care to patient populations. Identifying unique and specific aspects of the role that can impact appropriate and effective utilization of health resources and optimize health outcomes is also a significant factor in introducing a framework for ANP in the current healthcare climate.

Project Scope and Intent

The purpose of this project is to create an ANP framework for practice in an IBD Support Service that optimally impacts the quality of life and health outcomes for the IBD population. This has been accomplished through 1) an integrative literature review, 2) an examination of current knowledge of best practices in nurse-led support programs focusing on chronic disease management, and 3) concludes with a framework for ANP within the context of IBD.

I began the project by undertaking an integrative examination of current literature primarily focusing on the experience of living with IBD to broaden my understanding of the issues faced by this population. In order to integrate the literature review, I focused my literature search to studies pertaining to the lived experience of IBD patients from a qualitative perspective to reflect the theoretical and philosophical focus of my practice founded within a phenomenological standpoint. An exhaustive search of the current literature did not produce sufficient qualitative studies in the area of lived experiences of patients with IBD. However, I did find a number of quantitative studies to provide further insight into quality of life for this population. Additionally, I reviewed literature related to living with chronic disease and pain that is applicable to the IBD population, to augment the available literature specific to IBD.

The second component of the project provides a description of my examination of best practices in three nurse-led support programs that focus on IBD care and chronic disease management. Best practices are based on the synthesis of a systematic review of best available evidence, expert opinion and clinical judgment (Registered Nurses Association of Ontario [RNAO], 2002; Hickey, Ouimette, and Venegoni, 2000). Guidelines for practice are derived from the systematic review of best practices and provides guidance in clinical decision making in specific practice circumstances (Polit and Beck, 2008; RNAO, 2002). This component of the

project reflects my desire to articulate and create a framework for the role of the APN in IBD care.

In my practice as Case Manager for Gastroenterology, I have not found any formally established best practice guidelines for APNs working with the IBD population. The practices I have incorporated into my current role are derived from my years of experience working with patients who have IBD, many other patient populations, and from diverse practice settings. I have incorporated the knowledge gained through my formal nursing education, by attending presentations at conferences for GI nurses, examining reviews of current literature, and from discussions I have had during networking opportunities with nurse colleagues. I have also found that networking provides insight into my own practice as well as challenges me to reflect on my understanding about best practice and ANP. For these reasons, I included a segment in this project that provides further insight into current best practices, design of nurse-led programs, and the role of APNs in these programs.

Finally, this project culminates in a comprehensive framework for ANP within the context of IBD. A framework for practice is an important aspect of introducing a new role into a practice setting and outlining the scope and parameters of the role assists in establishing the contribution of ANP in nursing, for the organization, and for the patient population (Gardner, Chang and Duffield, 2006). In my practice setting, established ANP roles are virtually non-existent. The few Nurse Practitioner roles that were developed in other programs have since been replaced by roles such as “nurse navigators” and “nurse clinicians.” However, these roles do not depict ANP and it is important that I clarify the difference between these roles and my ANP role.

My role as Case Manager for Gastroenterology is the only autonomous population focused Case Management role that exists in my practice setting. Although I have the support of

the organization and physicians with whom I work closely to establish an APN role in the context of IBD care, I must also be certain to articulate an identifiable distinct level of practice that reflects the education, skill, autonomy, and level of decision-making that encompasses the competencies inherent in ANP. If I am successful in establishing this practice framework, I believe that this project will also lay the groundwork for the development of other population focused ANP roles in my organization.

In order to ensure that the literature review pertained to the theoretical and philosophical perspective I have identified as my foundational approach to this project, I began the project by reviewing literature pertaining to phenomenology as the key human science perspective in my practice, as the foundation for caring theory and, as the approach to examining the lived experiences of people with IBD.

Theoretical Perspective

Phenomenology as a human science.

The foundational basis of phenomenology began over 100 years ago in the work of Edward Husserl (1859-1938) who developed phenomenology as a philosophic and descriptive approach to inquiry of the human experience (Wojnar and Swanson, 2007). Husserl viewed phenomenology as “the study of how people describe things and experience them through their senses” (Patton, 2001, p.105). Underlying this view is the belief that phenomena need to be examined as they are consciously experienced, free from preconceptions and causal interpretation (van Manen, 2002).

Phenomenology is focused on gaining deeper understanding of the meaning of human experience through examination of lived experiences (Welch, 1999). In phenomenology, the essence of an experience is reflected upon by the individual participants and is consciously

translated into meaning through description of the experience as felt from within, as a state of mind (van Manen, 2002). A phenomenological inquiry is not as concerned with the facts of the experience as it is with whether the account is plausible in terms of whether it is true to the individual's sense of living it (van Manen). Phenomenology also allows for an examination of experiences that are shared among people who have lived with similar or common phenomena such as the lived experiences of health and illness (Benner, 1985).

A unique perspective of phenomenology is hermeneutic or interpretive phenomenology (Woljar and Swanson, 2007). The focus of concern for hermeneutic phenomenology is the interpretation of the conditions or context of human experience as understood by those who live it (Benner, 1985). Heidegger (1889-1976) developed this approach to phenomenology that was based on the premise that humans are situated in and constituted by their cultural, social, and historical contexts and bring that understanding to their interpretation and attached meaning of a lived experience (Woljar and Swanson).

As nurses who enter the illness experiences of our patients, we also bring interpretations of our own life experiences with health, illness, and nursing. This view is based on the assumption that our interpretations of the meaning of an experience can never be deemed objective, as we can not be separated from our unique experiences, values, beliefs and knowledge because we are also situated in and constituted by being in our world (Doane and Varcoe, 2005). Our situatedness, or position in the world, allows us to share meaning with others also situated in our world in ways such as a common language, customs, and practices (Doane and Varcoe). Being constituted makes nurses who we are by taking up our history, experiences, teachings and values and integrating them into our being and work as nurses (Doane and Varcoe).

Philosophical Perspective

Phenomenology and Watson`s theory of human caring.

Phenomenology is a human science approach that reflects the values, beliefs and assumptions of the discipline of nursing (Dombro, 2008). A philosophical approach such as phenomenology can be used to gain new and analyze current understandings of the inter-relationship of the nursing metaparadigm concepts of the person, environment, health and nursing (Dombro). Phenomenology can also serve as the epistemological foundation for a nursing research domain. In particular, the nursing domain of inquiry articulated by Newman, Sime, and Corcoran-Perry, (1991) as “caring in the human health experience” (p.3) provides a basis for a reflective analysis of phenomena of interest such as the lived experience of nurses in practice or, of caring in nursing practice.

Caring and the practice of nursing are often viewed as synonymous. However, it is important to determine how caring is conceptualized in order to apply the concept to a practice framework. Caring has been described in many ways including the essence, moral ideal, central concept, the mission, the art of nursing (Spichiger, Wallhagen, and Benner, 2005) and as an interpersonal relationship, an action, an attitude, and a fluid variable attribute (Brilowski and Wendler, 2005).

These concepts have been incorporated into a number of theoretical frameworks for nursing. The Theory of Human Caring was first developed by Jean Watson in the mid to late 1970s as a perspective that brought meaning and focus to the nursing discipline that was in the process of becoming a distinct health profession with unique knowledge, values, and practices (Watson, 2006). Watson (1994, p.3) describes caring as “the heart of nursing and the ethical and

philosophical foundation for our acts.” Watson continued to develop and evolve the original concepts of her theory over time.

Embedded within Watson’s Theory of Human Caring are the ten Carative Factors which serve as the guide to engaging in transpersonal caring relationships in nursing practice (Watson, 1994). The Carative Factors (Watson, 1994) are:

1. A humanistic-altruistic system of values
2. The instilling of faith and hope
3. Sensitivity to self and others
4. Helping-trusting human care relationships
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces (p.6).

Watson's Carative Factors (1994) have evolved over time, but the essence remains in the framework for transpersonal caring practice. Professional caring is depicted by Watson (1994, p.3) as “a special way of being in relation to self, other, and being in the world.” In caring relationships that a nurse develops with others, the nurse strives to “preserve the humanity, dignity, and integrity of self and others” (Watson, 1994, p.5). This type of relationship requires authentic presence and intentionality to engage in the healing processes of the other (Watson, 1994). Watson describes caring relationships as transpersonal meaning it is a mutual and

reciprocal relationship that goes beyond the self and allows us to engage in multiple ways of knowing, doing, and being (Watson, 1994).

The lived experience of patients is an important consideration when nurses engage in caring relationships in their practice. The meanings that a patient attaches to an illness experience need to be incorporated into the nurse's response to the illness situation (Watson, 2007). The nurse's ability to sense the importance of a patient's illness experience is essential to developing the conditions of caring practice (Watson). The phenomenal field that is created by the human interaction in an experience of caring is expanded to a more complex and deeper life pattern (Watson). When nurses enter this phenomenal field with patients, the art of caring is set in motion (Watson). This is the philosophical, moral, and relational perspective that I strive to maintain in my daily practice.

In order to engage in authentic transpersonal caring relationships with patients I care for in my practice, I need to continually focus beyond my self to better understand the experiences of others. In this way, I will uncover meaning and significance in their experiences and in my relationships with those I care for and in the work I do. The practice framework that I have developed for this project incorporates Watson's concepts of caring and transpersonal caring relationships into my daily practice within the context of IBD.

Focus Population

IBD is a term that describes two distinct forms of medically incurable bowel inflammation, Ulcerative Colitis and Crohn's Disease (Saibil, 2003). Crohn's disease may occur anywhere in the gastrointestinal system from the mouth to the anus (CCFC, 2009). However, Ulcerative Colitis only occurs in the colon and rectum and the only cure for the disease is to surgically remove the diseased portion of intestine (Saibil, 2003). To date, researchers have not

yet discovered a cure for Crohn's disease, but have identified possible predisposing factors, triggers, and medications that assist in controlling the disease (CCFC).

The symptoms of a flare-up of IBD are typically characterized by frequent daily diarrhea, abdominal pain, nausea, and fatigue (Saibil, 2003). The symptoms are the result of the inflammation, swelling, and ulceration of the lining of the intestine (Saibil). IBD is relapsing and remitting in nature, and may result in significant alterations in a person's lived experiences and quality of life.

IBD is now thought to be a result of the complex interaction of environmental factors with a genetic predisposition for IBD and a susceptible immune system (Danese, Sans, & Fiocchi, 2004). The Crohn's and Colitis Foundation of Canada [CCFC] estimate that 200,000 Canadians are living with IBD (CCFC, 2009). Men, women, and children of any age can be diagnosed with IBD however, most people are diagnosed before the age of thirty (CCFC). In a population-based study capturing the epidemiology of IBD in Canada, Bernstein, et al. (2006) described the trends in disease incidence across five Canadian provinces, which now serves as the IBD epidemiology database for Canada.

The intent of the study was to determine the public health burden of IBD in Canada as previous epidemiological studies pertained to populations in Europe and the United States. The researchers discovered that Alberta has the second highest incidence of Crohn's disease in the five provinces studied, second to Nova Scotia (Bernstein, et al., 2006). Alberta ranks third in the five provinces for incidence of UC with a rate of 11.0 per 100,000 people (Bernstein, et al.). The authors discussed factors such as a lower ethnic immigrant population, climatic, or environmental issues that may have contributed to the higher prevalence in Alberta and in small geographic areas with a higher prevalence of IBD (Bernstein, et al.).

Although a number of links and triggers to the development of IBD have been uncovered by researchers, treatment goals in the management of IBD are aimed at decreasing or eliminating the symptoms and, as a result, improving the quality of life for people living with the disease. Conventional treatments used to reduce the inflammation in the intestine that precipitate the symptoms of IBD and the immuno-suppressants and biologic medications used to alter the body's response to the inflammatory process (Steinhart, 2006) each have considerations that must be taken into account when determining a patient's medical treatment plan. The implications of these treatments are substantial and patients may be overwhelmed when faced with decisions to start treatment, as well as, issues regarding the long-term effects and health outcomes.

The unpredictable nature of both forms of IBD cause a physical, emotional, social, and spiritual toll on the lives of patients and their families. Quality of life may be affected even before a patient is diagnosed as patients struggle to find relief from the distressing and embarrassing symptoms that accompany the disease. Social isolation and stigmatization are still evident as patients enter the health system seeking treatment and relief from the debilitating symptoms.

Current research pertaining to quality of life issues for this population is essential in promoting understanding their lived experience and in developing strategies for nursing practice that will positively impact the lives of patients with IBD. The aim of this form of research is to broaden understanding of the personal, professional, and health system impacts of caring for patients who experience living with a chronic relapsing disease such as IBD. The relationship between the physical, psychological, and social impacts of living with IBD necessitates effective and holistic management of the disease (Hall, Rubin, Dougall, Hungin, and Neely, 2005).

I have taken this path in my ANP because I meet people with IBD in my everyday practice that provide me with inspiration to learn more about their experiences and to develop a practice that demonstrates respect and authentic caring for the person behind the disease. Since I began to focus on the population of patients who live with IBD, I became aware that health care providers do not always recognize the significance of living with a gastrointestinal disease. Many patients have told me that they have struggled through years of misdiagnosis or disregard for the symptoms until their health had deteriorated to the point that the symptoms could not be ignored. Some patients are labeled as “non-compliant” and “drug-seeking” when the treatment plan is not providing relief or is administered inconsistently. Patients have shared with me that they feel very alone and misunderstood and are reluctant to come to hospital because of how they are perceived.

Many people I have met who suffer from the daily physical symptoms of IBD have told me that they suffer in silence due to the embarrassing nature of urgent diarrhea, abdominal pain and fatigue. Some struggle to complete their education, develop relationships, maintain employment, and enjoy retirement while they strive to find a balance in their lives and allow their bodies to heal. Others are overcome by how quickly their lives can change and are faced with surgery, altered self-image, and even the risk of dying. I have watched families of these patients struggle to support the person with the illness and as the patient's role within the family unit changes dramatically within a short time frame.

I also reflect often on these patients' strength and persistence while they undergo loss of control of what is happening to their bodies and I am optimistic as they regain control and develop a life of relative normality. I share their optimism as they begin to see the life ahead of them and make sense of the struggles they have been through. Some of the patients who I have

encountered often in my practice have provided inspiration and encouragement throughout the development of this project as they recognize that they have a meaningful place in my experiences of illness, health, healing and caring. I plan to maintain this focus and perspective on the lived experiences of the IBD population by broadening understanding of their illness and health experiences through my ANP role so that I can play an important role in their achievement of optimal quality of life and health.

Methodology

Integrative literature review.

An integrative literature review provides a summary of past research from an exhaustive search of a body of literature pertaining to a particular subject (Beyea and Nicholl, 1998). The research reports are then evaluated using a systematic approach that ensures scientific integrity (Beyea and Nicoll). The process of conducting an integrative literature review provides a summary of the key concepts of the subject and identifies the strengths, weaknesses, contributions to, and gaps in knowledge regarding the subject (Colling, 2003).

Thirty peer-reviewed articles comprise the literature reviewed in this project. The literature search was filtered to include only peer-reviewed articles from scholarly journals written since 2004. Primary sources were obtained through an exhaustive search of major subject headings and key concepts for the project. A total of thirty articles were chosen based on specific inclusion and exclusion criteria. The criteria for inclusion in the review were based on quality of the research, relevance to the topic of lived experiences of patients with IBD, and potential contribution to the development of an ANP framework in the context of IBD. I excluded articles that were not based on quality research, not relevant to the lived experience of IBD or not useful to the development of an ANP framework for practice in the context of IBD.

The primary focus of the review was to examine the lived experience of IBD from a qualitative and phenomenological research perspective within the existing literature. I first focused the search on the key terms of “lived experience” and “inflammatory bowel disease.” This search only provided two articles. Both of these articles were based in the qualitative paradigm of phenomenology, met the criteria and were included in the review.

I then added the major subject heading “quality of life” to the search and obtained a total of 569 applicable articles. This literature search was conducted using a number of health related electronic databases, including CINAHL (59 articles), MEDLINE (312 articles), Health Source (43 articles), and Academic Search Premier (155 articles). I first excluded duplicates of articles that were distributed among the various databases resulting in approximately 550 potential articles. Some of these articles used qualitative methods and many used quantitative research methods.

I then combined the search with additional concept terms including “phenomenology,” “impact,” “coping,” “support,” “adjustment,” “chronic disease,” and “pain” to expand the potential articles that jointly pertained to the IBD population and to caring practice. This search did not elicit any additional articles that pertained to the key subject headings.

Using my defined criteria (quality of the research, relevance to the topic of lived experiences of patients with IBD, and potential contribution to the development of an ANP framework in the context of IBD), I identified 16 qualitative articles providing rich descriptions of the experience of living with IBD. All 16 of these articles obtained through the search were included in the review. In addition, using the selection criteria, I chose 14 quantitative articles pertaining to IBD and quality of life to comprise the thirty articles in the review. These quantitative articles were specifically chosen based on their relevance to the lived experience of

IBD, their usefulness in my practice working with people who have IBD, and to expand on the findings of the qualitative articles included in the review. I excluded articles from the search that were based in quantitative research that did not pertain specifically to the experience of living with IBD and did not provide further insight into ANP strategies working with this population.

Although I originally chose a qualitative phenomenological approach for the literature review, there are significant gaps in this area of research pertaining to people who live with IBD. I had hoped that I would broaden my knowledge of the experience of living with IBD through the rich narratives and thematic analyses that characterize qualitative research. Limiting my search criteria to articles written since 2004 also narrowed the available qualitative studies that could provide insight into the lived experience of IBD. However, I found that there was a significant amount of quantitative research that pertained to quality of life issues for the IBD population. After reviewing a number of the studies, I felt that they could contribute to the project by further focusing attention on quality of life which is a significant issue for people with IBD and ultimately is affected by their lived experiences.

To organize the studies, I utilized a chart that listed the source, purpose, sample, framework, concepts, design, and results of each study (Appendix A). I also included strengths and weaknesses of each study so that comparison and identification of gaps in the literature was more visible.

Throughout the integrative literature review I interspersed reflective practice experiences that demonstrate congruency between the findings in the literature contained in the review and the lived experiences of my practice population. In doing so, I was able to ground the literature in my practice and identify salient aspects of the research that support the ANP framework for the IBD population.

ANP in nurse-led support programs.

The second component of this project is an examination of best practices in nurse-led support programs that focus on IBD care or chronic disease management. I examined three advanced practice nurse-led chronic disease support programs to identify the nature of the advanced nursing practice role, preparation for the role, the nature of the program, and the philosophical and theoretical foundation of the program. In addition, the APNs were asked about best practices used in their program, important aspects of the nurse-patient relationship and how program outcomes are identified and analyzed.

The information for this component of the project is drawn from personal communication with three nurse colleagues I have networked, collaborated, and consulted with in my practice and who are providing a nurse-led service to their practice population. Although I was aware that each of the three APNs were providing nursing care to a population with chronic disease, I was not fully knowledgeable of the exact nature of their role, how the role reflected ANP, or if they had an established framework for their practice. I chose to examine one APN role in an inpatient palliative care consultant role, one in an outpatient clinic role for patients with IBD, and one in an entero-stomal therapy (ET) consultant role with a mixed focus on inpatients and outpatients. I began by communicating my intentions for this aspect of my project through email correspondence with a number of APNs and Nurse Practitioners in settings similar to mine who were providing care specifically to the IBD population.

The aim of this process was to compile best practice information specifically in IBD care that could provide a foundation of ANP that could be applied to my practice setting. Although I attempted to obtain more feedback from APNs working specifically with patients with IBD, I only received responses from two nurses in an ANP role who were working with that population. One of the nurses did not possess graduate education, had little experience with the population,

and had only been in the role a short time. Based on this information, I did not include her feedback in the examination of nurse-led programs.

This led me to approach two other nurses in ANP roles and include their feedback even though they were providing care to different populations. This situation unexpectedly provided me with more insight into the diverse roles of APNs working with populations outside of my population of interest. However, this experience may provide further support for the development of an ANP framework for a GI support service to provide structure for the introduction of new APNs into similar programs.

Advanced nursing practice framework.

I began the development of the practice framework for ANP in the context of IBD by utilizing a formatted process of developing, implementing and evaluating the role of the APN. This process resulted in a role description for the Case Manager - Advanced Practice (Appendix C), the implementation plan, evaluation process and long-term monitoring strategies. The competencies of ANP (CNA, 2008) are evident in the IBD Patient Assessment Tool (Appendix D), the goal and objectives of the IBD Support Service (Appendix F), and in the key practice domains of the role. The theoretical and philosophical perspectives of phenomenology and Caring Theory are integrated into the documents that comprise the framework. In addition, appreciation for and attention to quality of life issues for people with IBD as identified through the integrative literature review is a significant feature in each of the components of the framework that also includes an outline for health education for the IBD population (Appendix E).

Chapter 2 - The Lived Experience of IBD through an Integrative Literature Review

The Lived Experience of IBD

Stress, coping and support.

The stress patients experience leading up to and following the diagnosis of IBD can be substantial. The experience of being diagnosed with IBD has been examined in a qualitative phenomenological study exploring the strategies women used to cope with the diagnosis (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008) and in a quantitative study of how the perception of illness and coping strategies affects adjustment to the illness (Dorrian, Dempster, and Adair, 2009). Understanding how a person adapts to illness through coping strategies is an important aspect of providing ANP for the IBD population.

Themes that emerged from the investigations of Fletcher et al. (2008) depict the strategies that helped people cope with the phenomena of receiving a diagnosis of a GI disease. The most significant strategy affecting the women's ability to cope with the diagnosis was the involvement of a supportive network of family and friends (Fletcher et al.). In particular, support from a significant other is crucial due to the effect of the disease on the person's intimate relationships and ability to engage in everyday activities (Fletcher et al, 2008). Support from friends and family is also significant, and support from the community in areas such as public awareness, fundraising, and improving access to washroom facilities in businesses also impacts a person's ability to cope (Fletcher et al.).

Unfortunately, lack of support by friends and family is associated with feelings of guilt and isolation as people with IBD meet the challenges of daily life (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). However, guilt is also associated with the person's perception of the impact of the disease on their relationships (Fletcher et al., 2008). This perception adds to the

stress that people with IBD experience and further alters their ability to cope with the disease (Fletcher et al.).

Other coping strategies identified by patients in the three preceding studies include dietary alterations, seeking support, controlling the situation and surroundings, planning, improving attitude, relaxation techniques, denial, distraction and disengagement, increasing knowledge, religion, and the use of alcohol (Fletcher and Schneider, 2006; Fletcher, Schneider, Van Ravenswaay, and Leon, 2008; and Dorrian, Dempster and Adair, 2009). Dorrian et al.'s (2009) quantitative examination of perceptions of illness and adjustment to illness in 80 patients with IBD did not find a significant association between problem-focused or emotion-focused coping strategies and positive adjustment to illness. Problem-focused coping includes strategies such as planning, and suppression of activities (Dorrian et al.). Emotion-focused coping strategies include seeking emotional support, acceptance and denial (Dorrian et al.). The findings of this study also suggest that a person who perceives their illness as more severe, chronic, higher risk, and more symptomatic have poorer adjustment to the disease (Dorrian et al.). The authors place importance in addressing the illness perceptions of patients as a strategy to improve adjustment to having IBD (Dorrian et al.).

The role of psychological stress in IBD was examined in relation to gastrointestinal homeostasis and IBD pathophysiology (Hisamatsu et al., 2007). Psychological stress has been implicated in the course of IBD (Hisamatsu et al.). Hisamatsu et al conducted a literature review referring to a number of experiments in which increased intestinal mucosal permeability and altered bacteria-host interactions occurred in animal models that were exposed to stress (Hisamatsu et al.). The authors suggest that these observations are likely consistent with human IBD pathophysiology (Hisamatsu et al.). Patients in my practice who are experiencing increased

symptoms of IBD often tell me that they are experiencing more stress than usual which is consistent with these findings.

In one study included in the review, a seasonal fluctuation of relapse was noted in patients who completed a questionnaire naming psychological stress as the most prominent factor in their relapse (Hisamatsu et al, 2007). This is another observation I have made in discussions with some of the IBD patients in my practice. Some patients express that they tend to experience flare-ups of their disease only in the spring, while others tell me summer is their worst season for symptoms. These findings and observations exemplify the complexity of the interaction of environmental, immune system and genetics that predisposes people to IBD. It also supports my philosophical view that the lived experience of IBD can not be fully understood if not viewed in a holistic manner.

Patients I encounter in my practice share the view that support is critical to adjusting to living with IBD. I have found that spouses strive to be supportive in ways such as helping with household responsibilities, adapting their diets to that of the ill spouse, and participating in discussions regarding treatment and surgery. Parents of adult children also participate in the health experience by caring for grandchildren during hospitalization, assisting with financial issues, and providing a shoulder for patients who are struggling to cope with alterations in their health. Many of the patients express that they could not cope without their family and, in some cases, I have observed the relationship strengthening as the person with IBD and family members realize that the symptoms have a name and that treatment is possible.

I have found that some patients view the diagnosis as “a wake up call.” These patients take the diagnosis very seriously and alter their lifestyle and attitude about health as a method of coping with having a chronic disease. Their perception of the diagnosis of IBD is that they can

change the course of the disease by improving their living habits. These lifestyle changes often require the support of family members to participate in the changes and provide encouragement. In my experience, most patients attempt to cope with having a diagnosis of IBD and will require the support of their family and friends to attain positive adjustment to the illness.

Experiences of youth with IBD.

Although most of my patients are young adults in their 20's and 30's, I am caring for more patients in their late teens who have either lived with IBD since childhood and are transitioning to adult care, or who are just being diagnosed with the disease. The unique issues of youth and young adults living with IBD have been examined in three phenomenological studies that have been included in this review to highlight the significance of this disease in the young adult population (Lynch and Spence, 2007; Nicholas et al., 2007; and Savard and Woodgate, 2008).

Concerns related to IBD symptoms and treatments for flare-ups of disease were described frequently by the youth in a qualitative examination of their lived experience and quality of life (Nicholas et al., 2007). The disruptions caused by the flare-ups in their everyday life, at school and during hospitalization were significant concerns voiced by these patients (Nicholas et al.). The youth struggled with food restrictions, exhaustion and the overall lack of control over their lives (Nicholas et al.). Youth in this study expressed not feeling normal and were often reminded of their differences comparing themselves to their peers (Nicholas et al.).

In Lynch and Spence's (2007) qualitative study, four participants between 16 and 21 years who had been severely affected with Crohn's disease were interviewed to elicit information about their experiences since their diagnosis. The psychological difficulties that young adults experience as they struggle with IBD are often not shared with health care providers until a sense

of trust develops (Lynch and Spence). These authors enabled the young participants to share their experiences in order to inform and improve health care delivery for this population (Lynch and Spence).

This study highlighted the experience that stress is integral to living with Crohn's disease (Lynch and Spence, 2007). The youth revealed that the period before diagnosis was especially difficult as they struggled to understand what was happening and that took all of their time and energy just to cope with the debilitating symptoms (Lynch and Spence). However, between these struggles there were short periods of relative normality even though they lived in the space between fear of the return of symptoms and hope that they would remain well (Lynch and Spence). Social acceptance for these youth was accompanied by limitations on their lifestyle which further impacted their ability to cope (Lynch and Spence, 2007).

Young people who undergo surgery for IBD may be left with an ostomy that can impact their ability to participate in social activities and in building relationships (Lynch and Spence, 2007). The experience of youth living with an ostomy was also examined in a qualitative phenomenological study by Savard and Woodgate (2008). The youth in both of these studies either coped by hiding their ostomy or avoided the surgery in order to cope with the social stigma they experienced (Lynch and Spence). Coming to terms with an ostomy meant they had accepted their disease along with the altered body image that accompanied the surgery (Savard and Woodgate). The renewed sense of self was possible for these youth because of their improvements in health since undergoing the surgery (Savard and Woodgate). Allowing the young people to express their fears and frustrations assists health care professionals to understand their experience and offer support.

Lynch and Spence (2007) found that young people who had just received the diagnosis experienced a sense of shock and could not assimilate the information given to them about their disease. The youth expressed that time to absorb and integrate the information was needed (Lynch and Spence). Lack of understanding by school officials and employers was difficult for these youth (Lynch and Spence). Friends and family were viewed as helpful by reducing a sense of isolation but also added to the fatigue the youth experienced and potentially hindered their recovery (Lynch and Spence).

The treatment for IBD meant social and economic adjustments for the participants (Lynch and Spence, 2007). Side effects from medications were often perceived as difficult as the effects of the disease (Lynch and Spence). Cost of the medication was also a factor in how well the youth adhered to the treatment regime (Lynch and Spence).

The education and employment status of patients with IBD were examined in a literature review by Marri and Buchman (2005). The authors suggest that patients with IBD are likely to attain the same or higher level of education as control patients but may take longer to complete it (Marri and Buchman). Those patients who experience flare-ups of their disease during their education have significant impact on their quality of life (Marri and Buchman). This is compounded by an apparent lack of understanding by their professors and peers (Marri and Buchman). Patients who were employed experienced more sick days, however, most did not experience workplace discrimination due to their illness (Marri and Buchman).

These studies stress the importance of developing a trusting relationship with young people who are living with IBD. APNs who are involved in their care can assist in reducing their stress by providing time to absorb and reinforce information, offering assistance in improving the understanding of others, and addressing the impact of costs and treatment effects during periods

of illness. APNs need to acknowledge the feelings expressed by this population and encourage young patients to utilize their support network. If possible, finding a peer who is undergoing a similar experience can be a helpful resource for this group of patients (Savard and Woodgate).

Dimensions of health-related quality of life.

Wolfe and Sirois (2008) examined the dimensions of health-related quality of life (HRQoL) identified from the perspective of patients who were living with IBD through a secondary analysis of a quantitative survey. This qualitative study utilized the subjective lived experience of daily impact of IBD to illuminate the categories of HRQoL that affect this population. Two hundred and eighty-two Caucasian female patients with Crohn's disease were surveyed to answer the open-ended research question "How has IBD affected your daily activities?" (Wolfe and Sirois, 2008, p.877). Six broad dimensions of HRQoL were identified for analysis and the textual data from written narrative transcripts were explored to provide conceptual themes for HRQoL dimensions. The six main dimensions of HRQoL that were analyzed included physical, emotional, social, cognitive, self-regulatory, and practical (Wolfe and Sirois, 2008). These dimensions were not apparent in the quantitative aspect of this study and added to the author's knowledge of issues affecting the IBD population that is typically drawn through the use of HRQoL tools.

The first dimension provided insight into the function of the patients' bodies that impacted their HRQoL. The physical functions that affected the patients HRQoL were related to bowel movements, pain, nausea, energy, and vitality (Wolfe and Sirois, 2008). This aspect of IBD is common in all patients who live with the disease. In my practice experience, the physical functions affect all other aspects of patients' HRQoL.

The emotional dimension revealed concerns about anxiety, depression, fear, and loss of passion (Wolfe and Sirois, 2008). The social impact of having urgent and frequent diarrhea is one of the most salient concerns patients express in my practice. Every aspect of daily life may revolve around bowel movements. Patients often plan every activity from showering in the morning, eating lunch, and shopping for groceries around the need to defecate on an urgent and frequent basis. Passion for life is lost in the exhaustion that accompanies the constant attention to physical functions.

Social aspects of HRQoL in Wolfe and Sirois' (2008) study included reference to lack of understanding and value of their experiences, inability to participate, and acceptance. Planning of social engagements can also revolve around the symptoms experienced by patients with IBD. Choosing to participate in social activities may depend on accessibility to washrooms, and the exertion required to engage in the activities. Patients who limit their social activities can place a strain on their relationships with others and can impact how others perceive and understand their lived experiences of having IBD. I have noticed that the impact of social limitations is substantial in the young adult population in my practice. Some leave university, retreat to their bedrooms, and have difficulty developing new relationships as a result.

Cognitive issues identified from the patients' perspectives pertained to motivation, alertness, disposition, self-image, worry, and planning around the disease (Wolfe and Sirois, 2008). The dimension of self-regulation provided examples of how patients with IBD face their disease. For some, taking control of the disease emerged as a positive impact, while for others loss of control was expressed (Wolfe and Sirois). This dimension was expressed in the language the patients chose in describing how they manage their experiences such as, "I do," "I can," "I don't," "I have to," or "I feel" (Wolfe and Sirois).

Attaining health and normality.

Hall, Rubin, Dougall, Hungin and Neely (2005) conducted a qualitative study of the IBD population with a focus on 'health-related normality.' In this study, questionnaires, focus groups and individual semi-structured interviews were used to examine 31 individual patient experiences of illness, health seeking behavior and medication (Hall et al., 2005). Several themes emerged from the data including "restricted freedom" "health" and "normality" (Hall et al.).

The unpredictability of the symptoms of IBD affected every aspect of life for this group of patients (Hall et al., 2005). Being healthy meant that patients could freely conduct their everyday activities without having to compromise or sacrifice (Hall et al.). Normal bowel activity was the key for these patients in achieving freedom (Hall et al.). This concept of freedom also involved a continual reassessment of their health status in which the patients compared their health before a flare-up and after as well as to other patients with IBD, and healthy individuals (Hall et al.). This type of comparison allowed patients to view themselves as healthy when others were perceived to have more serious health issues (Hall et al.). The fight to regain as normal a life as possible involved the use of strategies such as positive attitude, diet, planning, social support and medications (Hall et al.).

Haynes and Watt (2008) studied the healthy behaviors in people living with debilitating illness to determine what sets these people apart from those who view themselves as ill. The concept of resiliency was the focus of the study (Haynes and Watt). This phenomenological study involved eight individuals who had been living with a chronic disease for at least six months and as long as 74 years.

The findings of this study placed spirituality and family support as key factors in maintaining quality of life and focus on health rather than illness (Haynes and Watt). Coping

with the chronic illness was learned through their live experiences and strengthened their commitment to living life successfully (Haynes and Watt). By focusing on others, these patients were able to successfully adapt to their illness and maintain supportive relationships (Haynes and Watt).

My practice experiences of patients who view the disease as a challenge to overcome often strive to improve their health through lifestyle changes and maintaining a positive outlook. The findings of Wolfe and Sirois (2008) demonstrates that proactive self-regulation strategies used by patients in this study were linked to self-efficacy in managing their disease and characterized by positive changes such as better eating and exercise habits. This finding supports the findings of Fletcher and Schneider (2006) in their phenomenological qualitative study exploring the relationship between food and the lived experience of women diagnosed with IBD and irritable bowel syndrome (IBS). In this study, self-efficacy is linked to controlling triggers and making adjustments in diet that results in improvements in symptom management (Fletcher and Schneider).

Wolfe and Sirois' (2008) segmentation of the daily lived experiences of HRQoL does not reflect a phenomenological perspective in which lived experiences are viewed in a holistic manner. Each of the HRQoL dimensions identified by the researchers in this study was compared to instruments used in IBD research to identify HRQoL measures affecting this population (Wolfe and Sirois, 2008). The dimensions were then allocated to the narrative descriptions in an effort to determine if commonly used HRQoL tools are truly measuring the lived experiences of IBD patients (Wolfe and Sirois). In particular, the quantitative nature of commonly used surveys do not typically include a narrative aspect that provides further understanding of the concerns of HRQoL that stems from the lived experience of patients with

IBD. However, the narratives included in this study express the essence of living with IBD that are recognizable in my practice population and provide knowledge of the issues affecting HRQoL.

Unseen pain.

People living with IBD are typically affected by physical symptoms including abdominal pain, diarrhea, and fatigue (Saibil, 2003). Pain associated with IBD can be both acute and chronic in nature. Although acute pain can be considered a universal human experience, chronic pain is a less universal phenomenon and, as a result, poorly understood and subject to stigmatization of the individual experiencing the pain (Clarke and Iphofen, 2008).

Clarke and Iphofen (2008) explored the lived experience of unseen chronic pain in their qualitative phenomenological study of 8 patients who were attending a nurse-led chronic pain clinic. They found that people who live with pain are prone to feeling isolated, deceptive, and distressed and potentially depressed (Clarke and Iphofen, 2008). The pain of Crohn's disease is typically associated with the deep inflammatory effects on the intestine and is worsened by the use of narcotic analgesics due to the slowing effect on intestinal motility (Canadian Pharmacists Association, 2004). The pain associated with Ulcerative Colitis is often related to the contractions and spasms of the colon and rectum (Steinhart, 2006). Non-steroidal anti-inflammatory drugs (NSAIDs) are known to cause inflammation in the intestine, so may intensify the pain the patient is trying to resolve (Saibil, 2003). Glucocorticosteroids are typically used as a first line treatment to reduce the inflammation associated with a flare-up of IBD (Saibil).

I believe that patients who are experiencing the pain of a flare-up of IBD benefit from an explanation of how the treatment will improve their pain by reducing the inflammation and

consequently feel that their pain is being acknowledged and maintain hope that it can be resolved. If not adequately addressed, the pain associated with IBD can affect the person's ability to maintain motivation and participate in daily living activities (Schneider and Fletcher, 2008).

I have learned in my practice to be direct and compassionate about the experience of pain in my patient population. I talk to patients who are admitted with a flare-up of their IBD about the effects of certain medications on their intestinal function and encourage them to try alternate techniques of pain management such as walking and relaxation exercises that may provide relief while the inflammation resolves. Patients I have met in my practice that have developed a dependence on narcotics for pain relief find themselves in a never-ending spiral of pain that is difficult to manage and creates an atmosphere that is not conducive to attaining health. This is an aspect of lived experience that I strive to improve understanding of in my practice and among health care professionals.

Physical health and nutrition.

The daily diarrhea that is the hallmark symptom of IBD can be distressing and magnify the psychological effects and quality of life for those living with IBD. In one quantitative study evaluating the burden of illness in patients with mild to moderate Crohn's disease, patients reported an average of three flares of their disease per year and 88% reported having diarrhea (Joshua-Gotlib et al., 2004). I have observed in my practice that it is not unusual for patients who are experiencing a severe flare up of IBD to have diarrhea every 30 to 60 minutes. A patient not experiencing a flare up of IBD may pass 3 to 4 stools daily. This can have significant impact on the wellbeing of patients who are trying to maintain everyday activities of life.

Bovenschen et al., (2004) studied the association between health-related quality of life and different presentations of GI symptoms in a quantitative study involving 873 patients who

were referred for endoscopic procedures. The purpose of this study was to determine if different types, amount and severity of GI symptoms led to differences in HRQoL (Bovenschen et al.). Patients completed questionnaires that rated the severity of their symptoms and measured their quality of life and overall health status (Bovenschen et al.). The results of the study indicated that the more severe, the greater the amount, and the more upper GI symptoms, the worse the patients rated their overall HRQoL (Bovenschen et al.). The researchers surmised that upper GI symptoms interfered most with essential activities of daily living such as eating and drinking (Bovenschen et al.).

This study is consistent with the experiences of patients with IBD in my practice setting who have both upper and lower GI tract involvement. Often nutrition is a major factor in their health and they may require nutritional support in the form of nasogastric tube feeding or total parenteral nutrition if they are unable to tolerate their diet orally. The decision to commence alternate feeding methods for IBD patients often coincides with a worsening of the patient's condition or a poor nutritional status related to prolonged disease. In another study, Childs (2006) described a case scenario that explored the decision-making process for determining appropriate nutrition support using Watson's Theory of Caring as a framework for a holistic approach to nursing assessment, history and care of the patient.

Childs (2006) stressed the importance of providing the patient with evidence of best practice to support decision-making blending practical aspects of care with the values based in a nursing theory. The guiding values embedded in Watson's Theory of Caring were extended into the nutritional assessment by taking a holistic approach to the assessment with consideration of the patient's desires, preferences, hunger, social environment, and emotional attachment to food, among others (Childs). The complete nutritional assessment would not only include physical

alterations with a focus on GI anatomy, weight, diet, intake and output but also includes medication, cultural and social history (Childs).

The patient in this scenario was no longer able to maintain his nutrition orally which in turn affected his overall HRQoL (Childs, 2006). Although the nurse recognized that alternate nutrition would be necessary, she also strove to provide oral nutrition as much as possible and offered the patient information regarding available alternate options to eating orally (Childs). This nurse included family members in information sharing and meaningful encounters with the patient (Childs). She stressed that in order for the patient and family to make an informed decision, the nurse and patient would need to establish a supportive helping-trusting relationship (Childs). This type of relationship would aid in developing goals of nutrition support while providing a holistic approach to practice.

Determination of diet.

Dietary implications in triggering the symptoms of IBD are a common concern of patients in my practice as they attempt to manage their disease by altering their diet. In a phenomenological study, Fletcher, Jamieson, Schneider and Harry (2008) examined the lived experience of eight women diagnosed with IBD and irritable bowel syndrome emphasizing their dietary patterns before and after diagnosis. The data was obtained through triangulation methods involving interviews, background questionnaires and food diaries (Fletcher et al.).

The salient themes that emerged from the data were “engaging in adverse behaviors, the importance of support, and issues with control” (Fletcher et al., 2008, p.187). The adverse behaviors were related to “dietary restrictions and issues with medications” (Fletcher et al., p.187). Dietary restrictions were either suggested by the health care professional, or self-imposed as a method to avoid triggers that worsened their symptoms (Fletcher et al.). Some women

restricted their own diets eliminating entire food groups which placed them at risk of nutritional deficiencies while others ate foods that they knew would trigger symptoms even though they realized this could be detrimental (Fletcher et al.).

The women who voiced issues with medications were prone to not taking their medications correctly or failing to take their medication that prevented exacerbations of symptoms (Fletcher et al., 2008). Some women took preventative medication to allow them to eat foods that were known to trigger symptoms or took preventative medications in excess, such as anti-diarrheal medications (Fletcher et al). The women expressed that they wanted to be “normal” and “live in the moment” even though they were engaging in adverse behavior (Fletcher et al.). The authors concluded as in Childs’ (2006) study, that a holistic approach to health and healing coupled with a positive relationship with the health care provider enhances the lines of communication to engage meaningfully in health education and problem solving (Fletcher et al).

Seeking control of symptoms through diet was examined in another qualitative study involving women who had been diagnosed with IBD or irritable bowel syndrome (Jamieson, Fletcher and Schneider, 2007). This study examined how the women tried to manage their conditions by determining potential triggers through a process of trial and error when they did not receive assistance from health care professionals (Jamieson et al., 2007). The women also sought diet information from alternate sources when they became frustrated with the process (Jamieson et al).

This study of the lived experience of determination of diet revealed themes similar to the two previous studies (Childs, 2006; Fletcher et al., 2008) including “engagement in adverse behaviors, the importance of supportive family and friends, and issues with control” (Jamieson et

al., 2007). The role of physicians in determination of diet for these women was one that often resulted in dissatisfaction and frustration when they were not able to get the advice they wanted (Jamieson et al.). Although IBD patients frequently seek relief of symptoms by altering their diet, research has not proven that diet will dramatically improve inflammation in either colonic Crohn's disease or Ulcerative Colitis (Steinhart and Cepo, 2008).

In my practice setting, the physicians will tell their patients that diet does not alter the course of their disease. This is similar to the experience of the women in Jamieson et al's. (2007) study. However, both the physicians in my practice and those in the study were supportive when patients attempted to reduce their symptoms by identifying and eliminating trigger foods (Jamieson et al.).

I speak frequently with my patients about the implications of diet on their disease and overall health and offer them support and guidance as they seek improvements in their symptoms. I also frequently collaborate with the dietitians in my practice setting so that we provide consistent and current nutritional information. I involve family members in the discussions regarding dietary measures as I have found that family members, while attempting to be helpful, can place additional burden on the patient who is trying to manage their illness by giving advice and chastising the patient for making unwise nutritional choices. A supportive family network and individualized nursing care can make the experience of determination of diet much easier and less frustrating for the IBD population.

Alterations in sleep.

Ranjbaran et al (2007) also found in a quantitative study that sleep disturbances were a common in the IBD population even when their disease was inactive. Normal sleep is essential for maintaining health, daytime function, and achieving optimal quality of life (Ranjbaran et al).

Altered sleep patterns can affect the immune system and as a result may worsen the symptoms of IBD (Ranjbaran et al). IBD patients in this study used more sleeping aids than controls and experienced difficulty getting to sleep and fragmented sleep due to a number of nocturnal GI symptoms (Ranjbaran et al). This is a common concern of patients in my practice setting who are experiencing a flare-up of their disease. I have observed that it is also an issue for patients who are prescribed glucocorticoids in their treatment plan. I have found it helpful to communicate the impact of active disease on sleep to my patients and encourage them to inform their physician if they are unable to achieve sound sleep.

Anxiety.

In their heuristic phenomenological study exploring the negative impact of IBS and IBD upon university-aged women, Schneider and Fletcher (2008) reported that anxiety was a frequent emotional reaction to the onset of symptoms such as diarrhea for many patients who have IBD. The anxiety experienced by women with IBD was viewed by some of the women as the precipitating factor for diarrhea (Schneider and Fletcher). This is perceived as highly distressing for people with IBD who are eating outside the home or in a public location and can result in feelings of helplessness, embarrassment, and guilt and also lead to social isolation (Schneider and Fletcher). Restricting, preempting and planning daily activities can significantly impact the quality of life for the IBD population (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008).

A daily health diary has been identified as a useful tool in identifying precipitating factors for anxiety and strategies used to prevent it (Schneider and Fletcher). A health diary is also a method of effectively opening communication between the health provider and patient so that a therapeutic relationship can occur and a mutual plan of action can be developed (Schneider and Fletcher). I have used a health diary in my practice for patients to monitor their symptoms while

waiting for the effects of their medical treatments. This allows the patient to better see the progress of their improvements in health on a day-to-day basis and provides a tool to communicate sensitive issues such as number of bowel movements per day to their health care providers. For some patients, the health diary helps them to put their symptoms in perspective and encourages them in their achievement of health.

Fears and managing illness.

To illustrate the benefits of IBD patients participating in developing a plan of care and managing their illness, Irvine (2004) conducted an interview of clinic patients to determine their most salient issues for patients with IBD, to identify the barriers preventing health care providers from meeting these needs and to develop strategies to respond to these needs and ultimately optimize patients outcomes. Irvine (2004) also reviewed literature pertaining to comparative studies and confirmed the study findings that the most important measures of illness outcome for patients are satisfaction and quality of life.

The most prevalent fears expressed by IBD patients in Irvine's (2004) study included living normal life expectancy, having a family, keeping a job, ability to do normal daily activities, and their children developing the disease. Patients in a retrospective quantitative study investigating the long-term HRQoL inpatients treated for enterocutaneous fistula also feared getting cancer, needing surgery, and complications (Visschers et al, 2008). Common concerns in Irvine's study included knowing how to identify a flare-up, medication side effects, and affording treatment.

Patients requiring surgery identified experiencing altered sexual function and had difficulty raising and addressing the issue with their physician (Irvine, 2004). Some of the patients experience night-time incontinence related to their surgery and experienced sexual

dysfunction as a result of the fear of having an accident during intimacy (Irvine). Body image may also be affected by surgery, complications of IBD such as fistula, and the effects of medications used to treat the disease. Although sexual health is identified as a salient concern for people with IBD, research on the subject is sparse and unfortunately overlooked in healthcare settings.

These studies illuminate the importance of discussing the fears of patients who have IBD. In my practice, patients occasionally identify fears pertaining to sexuality. Recognizing this is a sensitive topic for many people, I tend to incorporate aspects of sexuality into my discussions with patients in a general and non-intrusive way. For example, when discussing medications that patients are receiving or may require, I discuss issues of fertility including pregnancy, sperm production, birth control and impotency. I believe this opens the lines of communication to discuss pertinent issues of sexuality or fears that patients may have been reluctant to discuss. I also have experienced that many patients have a fear of colon cancer and I strive to keep them informed of their relative risk of colon cancer related to IBD. I also relate the need for surveillance and healthy lifestyle to ensure they are followed by their physician over time to minimize their risk.

Treatment concerns.

Treatments for IBD can be a source of relief for patients who are experiencing the debilitating symptoms associated with a relapse of disease. One of the most recently developed medical therapies is Infliximab, a biologic medication that alters the immune response in patients with active IBD (Steinhart, 2006). Banovic, Gilibert and Cosnes (2008) assessed the impact of Infliximab given intravenously versus conventional medical treatment given orally on the

subjective quality of life and on the evaluation of the state of health of 51 patients with Crohn's disease (Banovic et al., 2008).

The authors compared global improvement scores related to treatment and scores indicating the patients' point of view concerning their own state of health. Their findings suggest that the mode of treatment had no effect on either score (Banovic et al., 2008). Quality of life was also not affected by the treatment although the authors expected that patients who were receiving intravenous therapy would perceive their quality of life slightly worse by the inconvenience of more hospital visits for infusions and experience a higher rate of infection (Banovic et al.).

An interesting finding was that despite the fear of side effects with Infliximab, patients considered the efficacy of the drug more than they did the side effects (Banovic et al, 2008). The authors suggest that patients may overestimate the benefits of the medication and underestimate the side effects because they perceive that the drug is effective (Banovic et al). The patients were also more likely to adhere to the infusion schedule of Infliximab over adherence to taking oral medications (Banovic et al). By adhering to the treatment, these patients may be experiencing improvements in quality of life that match that of patients who are taking oral therapy.

Hall, Rubin, Hungin, and Dougall (2007) assessed IBD patients' medication beliefs using grounded theory principles in a qualitative study to determine how the beliefs related to medicine taking and other health related behavior. Individual interviews, focus groups and additional comments from participants were used to produce the text for analysis. The medication experiences of the patients were analyzed with a focus on their acceptance of and perceived necessity of the medication (Hall et al., 2007). The fears and concerns toward their medication

and perceived impact of their illness and symptoms on their lives and their willingness to self-manage were also explored (Hall et al.)

In this study, patients accepted the necessity of taking medications over time and this was linked to acceptance of the illness (Hall et al, 2007). Medication taking for these patients had become a part of everyday life and as the symptoms subsided, the medications were viewed as a normalizing factor in their lives (Hall et al.). Patients who “tested the water” (Hall et al., p. 3) by stopping their maintenance medication experienced worsening of symptoms that reinforced the necessity of continuing the treatment.

Fears and concerns about some of the medications, including glucocorticoids, prevented some patients from seeking health care (Hall et al., 2007). Fear of surgery was often the incentive to keep taking prescribed medications and to seek health care when feeling signs of a relapse (Hall et al.). The fear of what may happen on a daily basis if medications were not taken also reinforced the perspective that the medications were important in controlling their symptoms (Hall et al.).

Hall et al. (2007) found that two thirds of the patients in their study were keen to self-manage their medications and the most common medication kept at hand for symptoms of relapse was glucocorticoids. These patients expressed that they wanted to avoid bothering the physician, did not want to wait for an office appointment and felt confident in adjusting their dosage, although often sought permission to do so from their physician (Hall et al.).

The implications of these findings in practice suggest that patients make decisions about treatment based on their perception of the benefit and that the perception may change over time. This is a phenomenon that I experience frequently in my practice population. For example, all of the patients have taken glucocorticoids at some point in the course of their disease. Patients

recognize that this medication will improve their symptoms quickly and most recognize that continued treatment with these medications may lead to undesirable side effects. Some of the patients self-manage their symptoms and are successful in maintaining control of the disease.

I discuss the appropriate use, effects, side effects and potential harmful effects of corticosteroids with all patients with IBD in my practice. Recognizing that patients may make decisions about continuing or altering their treatment based on their perception of benefit of the treatment makes this an essential component of caring for these patients. I also encourage the patients to report any untoward effects to their physician and discuss how these effects may be managed more effectively rather than altering the treatment without the physician's knowledge.

A significant number of patients in my practice require biologic medications to treat their disease. I review information about the medication with each patient prior to starting the infusion or injection schedule. Many of these patients have not responded or lost response to conventional therapy and view the medication as “their only hope.” It is important that they understand that no medication is fully effective in all patients, yet they also need to understand that there are significant benefits and risks associated with taking medications. My practice framework incorporates a structured process of informing patients of the issues surrounding the therapies that are used in treating their IBD so that they can make informed decisions about their treatment and successfully participate in managing their disease.

Knowledge.

A quantitative study examining IBD-related knowledge, quality of life and use of complementary and alternative medicines was conducted to contrast two IBD populations, Chinese and Caucasian (Leong et al., 2004). IBD has not been prevalent in Asia however the incidence is rapidly increasing (Leong et al.). The low prevalence may be contributing to a lack

of IBD-related knowledge in the Asian population, whereas in Western countries, IBD is more prevalent resulting in improved knowledge of IBD. This was confirmed in Leong et al.'s study but the low prevalence of IBD in the Asian population did not adversely affect quality of life for those included in the study.

Patients in the Asian sample were generally treated by their physicians the same; regardless of whether they had Crohn's disease or Ulcerative Colitis (Leong et al.). In addition, they were less likely to have access to biologic medications that were available for the Caucasian population (Leong, et al.).

Patients in the Caucasian group were as likely to use complementary and alternative medications as the Asian population (Leong et al.). Caucasian patients were more likely to use complementary and alternative medications if they did not respond to conventional treatments or if they had a desire for a more holistic approach. The lack of IBD-related knowledge in the Asian population did not appear to influence their use of alternative treatments which suggests that these approaches are well accepted in this population.

IBD-related information is typically published and available in English, or French in Canada. Leong et al.'s (2004) study identifies the need for culturally sensitive care for other populations. My practice framework incorporates IBD-related educational materials that are published in various languages. Cultural aspects of illness interpretations are important considerations in ANP.

Gaining control and attitude.

A sense of control is a significant factor in a person's ability to cope with IBD (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). The constant awareness of the disease and recognition of potential triggers to the symptoms makes controlling the conditions and

environment around them difficult and, at times, impossible (Fletcher et al, 2008). Dorrian, Dempster and Adair (2009) measured illness perceptions and coping strategies in a quantitative study and concluded that symptoms of illness may be attributed to IBD when they may be unrelated to the condition leading to poor adjustment to the diagnosis.

Patients can perceive that control is less within their power when they are outside their home than when they stay at home, and efforts to maintain control can become all consuming (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). Failed efforts to control their situation often leads to a cycle of stress, increased loss of control and increased GI symptoms in patients with IBD (Fletcher et al., 2008). However, efforts to control factors in their environment that affect their ability to manage their condition may be viewed as an effective method of adjusting to living with IBD for some (Fletcher et al.) and not effective by others (Dorrian, Dempster and Adair, 2009). Those with frequent exacerbations, hospitalizations, or requiring surgery may not achieve a sense of control of their disease (Dorrian et al., 2009).

The attitude of people who live with IBD is self-perceived as an important component of effective coping (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). Women with IBD who focused on having a positive attitude gained a sense of acceptance and encouraged them to view themselves as having strength while living with the disease (Fletcher et al., 2008).

Techniques identified by patients to cope with stress impacting their disease include relaxation, exercise, self-talk, taking time for themselves, and time management (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). Distraction and ignoring the problem were also techniques used to cope with the effects of IBD (Fletcher et al., 2008). The use of these techniques may be dependent on the severity of the effects experienced by people with IBD and

Fletcher et al. (2008) found that if the effects are severe enough, people are likely to withdraw from activities completely.

Psychological distress.

Psychological distress is higher in people who perceive their disease as more severe and report poorer adjustment to the disease (Dorrian, Dempster and Adair, 2009). People who understand their disease are less likely to report psychological distress (Dorrian et al., 2009). The impact of psychological and disease factors on concerns and other variables of HRQoL was examined by Mussell, Böcker, Nagel, and Singer (2004) in a quantitative study involving 72 patients with IBD.

In Mussell et al.'s (2004) study, the dependent variables were disease-related concerns, psychological symptoms, and somatic complaints. The predictor variables were identified as coping with illness, health locus of control and disease (Mussell et al.). These researchers identified that women experienced more intense concerns than men and no difference was found between patients with Crohn's disease or Ulcerative Colitis (Mussell et al.).

Concerns that were significant for patients included effects of medication, having an ostomy bag, uncertainty of the nature of the disease, being a burden, energy level, loss of bowel control, having surgery, among others (Mussell et al.). These concerns were predicted most often in patients who demonstrated depressive coping such as irritability, social withdrawal, and feelings of helplessness (Mussell et al.). Additionally, patients who demonstrated active problem-solving coping such as actively seeking information and fighting against the disease also produced more intense concerns and somatic complaints (Mussell et al.). The authors attribute this finding to the actual limitations of the patient to successfully influence the course of their disease with coping strategies (Mussell et al.).

Although the sample size of this study was relatively small for a quantitative analysis, and all of the patients were in remission, the authors suggest that patients who exhibit depressive coping may benefit from psychological interventions in conjunction with medical treatment (Mussell et al.). In my practice setting, social workers and psychologists are not members of the team caring for IBD patients, so psychological support is provided primarily by the APN. Identifying coping strategies used by patients in daily life is useful in determining disease-related concerns, minimizing somatic complaints and psychological distress.

Socioeconomic impact.

Sainsbury and Heatley (2005) conducted a literature review to examine the psychosocial factors affecting quality of life in patients with IBD. The authors reviewed 107 studies that pertained to psychological, social and demographic characteristics of quality of life (Sainsbury and Heatley). This study revealed that quality of life is more affected in females than males with IBD, they rate their symptoms as more severe and their disease is more extensive (Sainsbury and Heatley).

IBD patients who live in lower socioeconomic communities tend to have increased morbidity, reduced quality of life scores, more relapses, and inability to sustain employment (Sainsbury and Heatley, 2005). However, the socioeconomic level of patients with IBD in many of the studies appears to be equal or higher than that of the background populations (Sainsbury and Heatley). This finding suggests that socioeconomic status is a contributing factor to reduced quality of life in the IBD population and attention to access to treatment, support and follow-up is particularly important in the role of the APN for people with reduced socioeconomic status.

In my practice, socioeconomic status is often an issue in developing a plan of care for patients who require expensive medications. Patients will alter the amount of medication they

take based on their financial situation and what they feel they can afford. I investigate financial concerns early in our professional relationship to identify any potential issues that may arise as the treatment plan develops. If the patient requires income assistance, I help them navigate the community agencies to access appropriate resources. By improving access to needed financial assistance, I find that patients are more apt to adhere to their treatment plan, experience less psychological distress and, as a result, maintain a higher level of health.

Health education and achieving health.

Information and education about IBD that is provided at the time of diagnosis was found to be important in ability to cope, but is less useful for people who have lived with their condition for a number of years (Fletcher, Schneider, Van Ravenswaay, and Leon, 2008). Access to information and education about IBD helps people realize that they are not alone in coping with their disease (Fletcher et al, 2008). These studies underscore the importance of identifying a supportive network and introducing early education strategies to improve coping ability in the IBD population, allow them to adjust to living with the disease, and optimize their quality of life.

Patients who are not able to achieve control for their symptoms despite traditional medical therapy may seek alternative measures to manage their illness, some that may augment their medical treatment, others that may not. One of the most effective ways of maintaining health in the general population is through regular low-intensity exercise (Public Health Agency of Canada, 2005). People who live with IBD may avoid exercise in the belief it may exacerbate the symptoms of their disease or due to the lack of energy and fatigue that often occurs in active IBD. Yet, a randomized prospective quantitative study examining the effects of low-intensity exercise on a group of patients with mildly active Crohn's disease demonstrated statistically significant improvements in quality of life measures after a three month program of walking for

30 minutes three times a week (Ng, Millard, Lebrun, and Howard, 2007). These patients also reported less fatigue and more energy with a more positive outlook about life and their disease (Ng et al., 2007).

These studies provide substantiation for the need and desire of patients with IBD to manage their disease and achieve health and normality. The sensitive and difficult nature of some of the fears held by patients prevents them from expressing them and seeking assistance to resolve them. Physicians may not spend sufficient time with the patients during office visits as physical issues and medical treatment may take precedence. The APN involved in the care of the IBD patient has the opportunity to alleviate fears and assist patients in taking control of their disease through the use of transpersonal caring, disease related and health promoting education, use of resources, and ongoing support for this population.

Jäghult, Larson, Wredling, and Kapraali (2007) created an educational program for IBD patients and conducted a randomized control trial to assess whether the program would improve health-related quality of life for the participants. The ninety-three patients included in the study were randomized to either an intervention or a control group (Jäghult et al., 2007). The intervention group attended the education program and the control group received regular information (Jäghult et al.). All participants completed questionnaires measuring health-related quality of life (Jäghult et al.).

Although the researchers expected that HRQoL would improve following a multiprofessional education intervention, no improvements were seen in the study sample (Jäghult et al., 2007). One of the explanations was that the HRQoL instruments used in the study may not have been sensitive enough to measure the effects of the education program or the

patients were not in remission at the time the questionnaires were administered causing a reduction in HRQoL (Jäghult et al.).

The only significant improvement in the study was found six months post-intervention in the disease-specific questionnaire rating important worries and concerns of patients with IBD (Jäghult et al.). This finding suggests that the participants found the information helpful and informative, thereby reducing their worries and providing them with strategies to manage their disease. In a similar study conducted by Oxelmark, Magnusson, Löfberg, and Hillerås (2008), the authors also concluded that HRQoL was not affected by a group-based education program for IBD patients. However, for patients who had a short duration of disease, significant improvements were seen in measurements of disease symptoms, social, and emotional factors as well as measurements of coping capacity (Oxelmark et al, 2008). This finding suggests that educational programs conducted early in the course of a person's illness may positively affect their experience and coping ability.

In my practice, I am more likely to provide disease-related education on an individual patient basis, but would now incorporate follow-up with all of the patients. Follow-up would be an important intervention to ensure that the patients' actual issues are being addressed, as they would change over time and according to the course of their disease and life circumstances. Many patients I meet have developed some knowledge of IBD as they have often been through a number of investigations and physician visits leading up to their diagnosis. As the APN involved in their care, it is also important to confirm their level of understanding and add to their knowledge appropriately through a supportive ongoing professional relationship.

Hospitalization and caring relationships.

Hospitalized patients' experiences of illness are further impacted by over-burdened health systems, over-worked health care professionals, and short lengths of stay. The spirituality and wellbeing of hospitalized patients can be affected by the relationship with the health care professional. The concepts of hope, spiritual wellbeing, and quality of life in hospitalized patients was examined using a prospective, longitudinal, descriptive design (Pipe et al., 2008). Using Watson's Theory of Human Caring as a conceptual framework, the authors explored the relationship among hope, spiritual wellbeing, quality of life and length of stay in a sample of 48 hospitalized patients across the continuum of care from admission to 6 weeks after discharge (Pipe et al.).

In this study, the needs of patients and resulting interventions were identified in the nurse's charting (Pipe et al., 2008). However, behaviors that indicate knowing the patient through a transpersonal caring relationship were less evident in the charting (Pipe et al.). Listening, being present, offering encouragement, and other caring behaviors have been linked to patient safety and reduction of harm as well as improvements in hope, spiritual wellbeing and quality of life (Pipe et al.). These improvements can potentially impact overall length of stay for patients requiring hospitalizations (Pipe et al.). This study provides important substantiation for the integration of the concepts of a theoretical framework such as Watson' Theory of Human Caring in everyday nursing practice.

Summary of Integrative Literature Review

The integrative literature review of the lived experiences and quality of life issues for the IBD population has illuminated a number of key priorities for my ANP working with this population. By taking a phenomenological perspective and combining concepts of caring theory

with my practice experiences gleaned from working with the IBD population, I have identified a number of areas that I can positively impact through ANP. The most salient issues for this population were clearly identified throughout the literature and I was able to reflect on my practice further substantiating the findings in the research.

One of the key themes identified for this population is "coping" with the diagnosis, the symptoms, impact on quality of life, with treatment and attaining and maintaining health. The ability to cope is affected by trusting professional relationships with care providers and through a supportive network of family and friends. Patients that employ coping strategies such as stress management, lifestyle adjustments, balance in social and work life, and realistic illness perceptions are more likely to adjust to living with a chronic disease such as IBD.

Studies included in this review that address HRQoL issues suggest that the impact of the disease on HRQoL can be positively affected through a transpersonal caring relationship with a supportive health care provider. Access to information early in the course of disease is important in impacting adjustment to illness and successful management of symptoms and maintenance of health. Education programs, although helpful and appreciated by patients with IBD, may not provide significant impact on improving overall quality of life. Involving patients in individualized education, holistic care planning and participation in goal setting may have more impact on overall HRQoL.

Addressing salient issues such as symptom management, diet alterations, exercise, sleep, and sexual concerns are viewed as important aspects of health care for this population and need to be incorporated into the APN practice framework. Treatments, including medications, complementary therapy and surgery are all issues that are of significance for people with IBD. Education about these aspects of living with IBD need to be individualized according to the

needs expressed by the patients and reinforced over the course of the professional relationship as the education needs will change over time.

All of these findings can be incorporated into best practices of APNs working with IBD populations. The authors did focus on the nature of the health care provider relationship with patients and stressed that a trusting supportive relationship was most conducive to health for this population. The next component of this project was to examine how APNs in nurse-led support programs incorporate best practices into their respective programs. This aspect will provide additional knowledge that I will incorporate into the practice framework as the final component of this project. The components of the three programs I reviewed are identified by the nature of the program, the APN preparation required for the role, the focus of the program, the key aspects of the APN role, theoretical and philosophical foundation for nursing practice, best practices and the APN's perspective of key aspects of the patient-nurse relationship in their program (Appendix B).

Chapter 3 - ANP Framework

ANP in Nurse-led Support Programs

The first program I examined was an inpatient palliative care, consultation service. This program is situated in a large urban teaching hospital and is an interdisciplinary in nature. The nurse in this program identifies herself as an APN and her title of Clinical Nurse Specialist (CNS) reflects the accepted ANP role as described by the CNA (2008). She is a master's prepared nurse with additional education and expertise in the field of palliative care. She does not identify herself as the leader of the program, but instead indicates the program is based on a shared leadership model.

The primary focus of her program is to provide consultation on clinical issues pertaining to the palliative population and their families. Consultation requests are submitted to the program by clinical staff including physicians, nurses, and allied health professionals. The CNS meets the patient and family on the palliative care unit and reviews the issue of concern. Once the concern is clarified, the CNS makes recommendations, consults other health care providers, or provides information for patients and families to access additional resources. Follow-up by telephone in the community is also available should palliative patients be discharged to their home.

The Palliative Care CNS related that she incorporated theoretical perspectives such as humanistic theory (Paterson and Zderad, 1976) and concepts of relational practice into her practice. Humanistic nursing places meaning in the act of nursing as a conscious responsible transactional relationship with an awareness on the part of the nurse of the experience of self and the other (Paterson and Zderad). This theoretical perspective fits within the phenomenological paradigm. She indicates that her practice is based on a post-modern perspective, although this perspective is not formalized in her practice setting.

The best practices used within the Palliative Care consultation program are established through the Canadian Hospice Palliative Care Association. This national association provides guidance for practice in palliative care by offering educational resources and standards of care in the practice of palliative care nursing (CHPCA, 2009). Although Palliative Care certification for nurses is available through the Canadian Nurses Association, this nurse did not intend to obtain it. She did, however, focus her graduate education on the Palliative Care population.

The aspect of the nurse-patient relationship that the Palliative Care CNS felt was most important was a caring presence and focus on relational practice. This focus is evident in her choice of theoretical and philosophical basis for her practice and the nature of palliative care

nursing. Finally, the CNS indicated that outcome measurements of her program activities or the health of her patient population were not collected, but were needed to monitor and evaluate the effectiveness of the program.

My evaluation of this program and ANP role allowed me to compare the similarities between my current practice and that of an established CNS role. The theoretical and philosophical perspectives of the program are similar to my chosen perspectives for my practice setting. The models and guidelines for best practice in Palliative Care nursing are more developed than Gastroenterology nursing, but the national organizational structure in my specialty field is similar to that of Palliative Care.

The second program I evaluated was an outpatient IBD clinic interdisciplinary program in which a CNS works with a team of Gastroenterologists and a GI fellow. Although she is one of two CNSs, this nurse does not identify the role as leader of the program. She instead indicates that leadership is collaborative and her practice is in conjunction with the practice of the Gastroenterologists.

This nurse has Master's of nursing education along with advanced education in pediatric gastroenterology. She does not clearly identify herself as an APN, or a Nurse Practitioner however she initiates investigations and treatment on her own. Her primary role in the program is to act as liaison between patients and the Gastroenterologists as the interdisciplinary coordinator of care. The focus of the program is to assess IBD patients on an outpatient basis, provide education and refer patients to research trials within the practice setting. This CNS also assists IBD patients by facilitating emergency visits and admission to the hospital.

The role also includes provision of education regarding medications, completing insurance forms with the patient, and reviewing laboratory results. The APN responds to

telephone inquiries from patients, provides psychosocial support including health system navigation. Navigation is a function of the role in which the APN guides and empowers patients to access the various departments and agencies needed to receive health services. She is able to collaborate with the department of nursing education at her worksite to provide nursing education about IBD. The nurse also assesses patients' eligibility for inclusion in study protocols and makes recommendations to the Gastroenterologists on the patients who may benefit from clinical trials.

This APN does not identify any specific theoretical or philosophical approach to her practice. She does not utilize any formal best practice documents in her practice but indicates that a Gastroenterology fellow is preparing a document that will be used within the health region. This nurse suggests that Nurse Practitioners are the best fit for her role, and attributes this to the amount of prescribing of medications and ordering tests that is required in her practice setting.

The outcome measurements collected by this nurse includes service logs reporting time spent talking with patients and communicating with others. This information is sent to Alberta Health Services to capture the workload of the APN. Finally, this APN indicates that the most important aspect of her role is that of patient advocate.

The last nurse-led program I evaluated was the Enterostomal Consultative Service that is lead by two APNs who report to community care. This APN has Master's of nursing education with additional clinical specialization in enterostomal therapy. The role of this nurse has a large clinical component and is intended to develop capacity in patients and health care providers that reflects the best available evidence for best practice in wound and ostomy care. The majority of her time is spent in direct consultation with patients in person, by telephone, and in some instances, by email.

The service model used in this program is based on the organization structure of community care in her practice setting. The professional practice role is comprised of policy and procedure development, researching best practices, program development, and coordinating regional supplies and products. The clinical practice role provides consultation for complex care issues, problem solving, care planning, coordination of care, and patient and family education. Staff education is a primary role for the enterostomal therapy APNs and is provided to many disciplines including the wound care team with members from across the health region.

This APN does not identify any theoretical perspective that guides her practice but instead incorporated aspects of a variety of perspectives. Her philosophical standpoint is based on appreciation of a person's own learning style and capacity, respect for a person's right to choose as long as the choice is well informed. She believes in a collaborative approach that supports a person's learning in a way that is meaningful and emphasizes the importance of respect. This APN feels that the continuity provided from hospital to home and ongoing in the community is the most important aspect of the nurse-patient relationship in her practice.

The best practices in the Enterostomal therapy program are derived from best practice guidelines from national organizations including the Registered Nurses Association of Ontario, National Pressure Ulcer Advisory Panel, The Canadian Association of Wound Care, and the Canadian Association for Enterostomal Therapy. The APN related that establishing best practices in her program would be enhanced by increased resources and time to develop, implement and evaluate the impact of implementing the practices. Data collection is limited to number, location, and types of visits made by the APNs. Patient outcome data has been discussed, but she indicates resources are not in place to capture and report the data.

Autonomy and collaboration are two key features of an ANP nurse led program from the perspective of the Enterostomal Therapy Nurse. In addition, she identified knowledge transfer as a key component of incorporating knowledge from other disciplines and developing a collaborative practice. This program is very successful in my practice setting and the nurses are acknowledged to have expertise in their field and are consulted regularly for wound care and enterostomal issues that pertain to my practice population.

These three nurse-led ANP programs each reflect aspects of my existing IBD support program. By examining each of them looking for similarities and differences, I am able to draw from each of their descriptions to build my framework for practice with the IBD population.

Advanced Nursing Practice Role

The CNA (2008) document *Advanced Nursing Practice: A National Framework* serves as the foundation of the ANP role I have developed for my practice. This document contains information about the "evolution of advanced nursing practice, definition and characteristics, educational preparation, roles, regulation, competencies, impact of advanced nursing practice, and support for advanced nursing practice (CNA, 2008, p. 8). There is growing recognition for the contributions and role of the APN in Canada and of the impact of ANP on the profession, the health-care system and on patient outcomes (CNA, 2008).

My role as the Case Manager for the department of Gastroenterology was initially developed in response to the burgeoning practice of the two Gastroenterologists working in my practice setting. They identified that their workload would be more manageable if a nurse with experience in Gastroenterology and ability to manage large patient caseloads could work in partnership with them to provide care to patients with gastrointestinal disease. I entered the

position with a background in gastroenterology nursing and several years of acute care nursing experience in a variety of settings, frontline and management positions.

My educational background included a diploma program, followed by completion of a post-RN degree program and a number of certification courses relevant to my practice setting. Even so, I realized that in order to develop my position into one that reflected an ANP level of nursing practice, I would need to prepare myself further with specialty certification and graduate education. To achieve my educational goal it was important that the goal was supported by my employer and the physician group in my practice setting. Once I obtained CNA certification in Gastroenterology and completed my praxis courses in the graduate program, I began the process of developing my skills in ANP.

The CNA (2008, p.10) describes ANP as "an advanced level of clinical nursing practice that maximizes the use of graduate preparation, in-depth nursing knowledge and expertise in meeting the health needs of individuals, families, groups, communities and populations." The Canadian Society of Gastroenterology Nurses and Associates (CSGNA, 2000) has issued a position statement pertaining to role delineation of the APN in Gastroenterology. This document reflects the CNA (2008) guidelines for ANP as well as the scope of practice of each provincial licensing body and the employer. Although graduate nursing education is not specified, the titles used in the document (Nurse Practitioner, Clinical Nurse Specialist, and Nurse Endoscopist) support the graduate level of advanced nursing education required for the role.

PEPPA Framework

I adopted a process for APN role development, implementation, and evaluation named the PEPPA framework (Bryant-Lukosius and DiCenso, 2004). The purpose of this framework is to overcome barriers to implementation and utilization of the ANP role through a "participatory,

evidence-based, patient-focused process (PEPPA)" (Bryant-Lukosius and DiCenso, 2004, p. 530). This process reflects the values and underlying principles of ANP while addressing the needs of a patient population through coordination of care and collaboration throughout the health continuum (Bryant-Lukosius and DiCenso, 2004). This framework was another guiding document in the development of my APN role and provided a structured format for the implementation of the ANP aspects of my role.

The PEPPA framework consists of nine steps to collect data to support the ANP role and introduce the model of care (Bryant-Lukosius and DiCenso, 2004). The stakeholder relationships that the APN has established within the context of multi-disciplinary care are viewed as the key to the conditions that can assist in facilitating or obstructing the development of the APN role (Bryant-Lukosius and DiCenso). The steps of identifying the elements of the process are as follows:

- "1. Define population and describe current model of care
2. Identify stakeholders and recruit participants
3. Determine need for a new model of care
4. Identify priority problems and goals to improve model of care
5. Define new model of care and the APN role
6. Plan implementation strategies
7. Initiate APN role implementation plan
8. Evaluate APN role and new model of care
9. Long-term monitoring of the APN role and model of care"

(Bryant-Lukosius and DiCenso, 2004, p. 532).

The first of these steps are addressed in the project proposal and first section of this project. The population is those with IBD who I encounter in my practice. The current model of care is Case Management for the IBD population. The key stakeholders are, first and foremost, the patients and their families. The health care team including the Gastroenterologists, nursing staff, and allied health staff are the key health care provider stakeholders. Another key stakeholder is the CSGNA, the national nurse interest group of which I am a member.

The health region administrators are the system stakeholders who have already provided endorsement of this project. In addition, Alberta Health Services has identified the priority need for access to quality, patient-focused care in a sustainable, efficient and effective health system (Alberta Health Services, 2009). Other community stakeholders include the Crohn's and Colitis Foundation of Canada (CCFC), the pharmaceutical companies and programs that provide IBD treatments, as well as, the health insurance industry that provides reimbursement for the treatments. Identifying the key stakeholders is the starting point for the next step of developing a new model of care for my practice.

The scope of my role as Case Manager was evolving and my responsibilities were increasing as my experience, education and the needs of the population were growing. When I determined that a framework for ANP in my role would be needed to further expand my role, I also determined that a role description for my practice setting was needed. At the time, I had not yet completed my graduate education and no other similar positions existed in my setting. I decided to develop the role description with the competencies for a Case Manager with an undergraduate degree and for a Case Manager with ANP competencies and graduate education to differentiate the aspects of the role I intended to expand. I believe that providing two

complementary but distinct roles for Case Managers in a specialty program would facilitate the introduction and acceptance of an ANP role in my, as well as other, practice settings.

Role Description

The CNA (2008) guidelines for ANP served as the foundational document describing the domains of practice I included in the role description I developed for my practice (Appendix C). I developed the role description in a generic manner so that it could be used within the practice settings of a number of specialty services.

The role description begins with a section outlining the scope of practice for the Case Manager and Case Manager - Advanced Practice. Scope of practice has been described by the College and Association of Registered Nurses of Alberta [CARNA] (2005, p.7) as "determined by the needs and health goals of their clients and is limited only by the specific competencies of the individual registered nurse to perform the activities necessary for the client population with whom that nurse works, within applicable legislation and agency policy." This document also indicates that registered nurses are able to "develop progressive expertise in caring for defined client populations" "through a combination of experience, continuing education and advanced education" (CARNA, 2005, p. 4). This broad description provides a foundation for the evolving scope of practice of my role as APN that is consistent with the role description I have developed for my practice setting.

The responsibilities of the Case Manager -Advanced Practice reflect the CNA (2008) core competencies for ANP. The competency categories of clinical, research, leadership and consultation (CNA) are embedded within this section of the document. Each of the core competencies have theoretical, research and nursing knowledge integrated with clinical experience in the criteria that APNs demonstrate in their practice.

Although navigation of health services is an important aspect of the APN role in the nurse-led programs I examined, as well as my own, the position of Nurse Navigator is becoming more common in my practice setting. The nurses in these roles are not necessarily APNs and do not meet the educational preparation requisites for ANP as outlined by the CNA (2008). I have chosen to focus the responsibilities and characteristics of the role primarily on the CNA (2008) competencies for advanced nursing practice, rather than the function of navigating the complexities of the health system. I believe this distinction will provide needed clarity between the APN role and that of other nursing roles and will assist in implementing the strategies I have developed for the practice framework.

Assessment Tool

The first competency that I focused on in my framework development is the clinical competency. I began by developing an assessment tool that encompasses the theoretical and research findings in the literature review, knowledge I gained through my clinical praxis experiences and my experience in the Case Manager role (Appendix D). I view this tool as a guide for documentation of the health and illness experiences of patients who require the IBD support services in my practice.

The primary objective of introducing the assessment tool in my practice is to provide an accurate and comprehensive picture of the IBD patients' health and illness experience. Although the tool can not be all-encompassing and address every experience or concern in a patient's life, it can serve as a baseline of information drawn from the patient's perspective for developing a mutual care plan, and as an ongoing record of the patient's progress toward attaining and maintaining health. Using a perspective of holistic care in conjunction with this assessment and

planning tool provides an opportunity to gain deeper understanding of patients' health and illness experiences and to develop transpersonal caring relationships in my practice.

This assessment tool reflects the caring concepts in Watson's Caring Theory (1994). Although the health organization in my practice setting does not articulate the need for caring theory in practice, the apparent absence of a theoretical basis for practice in my, and many other, practice settings calls for the introduction of a theoretical model for nursing. This was evident in my examination of nurse-led ANP programs and in particular in the programs for patients with IBD.

My practice is quite autonomous and the tools I develop in my practice may serve as models for other programs, but are typically used only by me for my practice population. This allows me the latitude to incorporate the concepts and values of Caring Theory into the document without the need to transform the worldview of the entire nursing department and organization. This will indirectly influence the perceptions of the organizational leaders regarding the advantages of ANP, caring practices, and how I demonstrate nursing praxis. This tool is one that could be shared among other APNs working with the IBD population.

The document provides an opportunity for the patient to express their health, educational and support needs from their perspective. The HRQoL issues that were salient in the literature review have been identified within the tool and would be discussed in more detail with the individual patients. The assessment tool also provides the starting point to develop a plan of care collaboratively with the patient and family and additional resources identified in the assessment.

Although the tool could be completed during the initial encounter with the patient, my intention is to complete the information included in the tool on an individual patient basis and focus on areas of importance as identified during the information gathering discussions. As my

relationship with the patient develops, health and illness related concerns voiced by the patient would be added to the document. In addition, I will use the document as the template of information to develop a written narrative history, up-to-date assessment, and care plan that will be kept on the patient's chart for reference by the Gastroenterologists and other health care providers.

The tool also contains reference to the Harvey Bradshaw Index (HBI), a disease activity index that is utilized by physicians in monitoring patients' progress and in authorization forms when accessing certain medications. Including this index does not imply that the experiences of the patient are of less significance, but instead creates congruency between the patient's health and illness experiences and the requirements of agencies involved in accessing care and treatments for this population.

The values and principles of Caring Theory may not be expressed directly in the document but the use of the assessment tool in practice will help to establish transpersonal caring practice with a holistic focus on the IBD population. However, the goals and objectives of the IBD Support Service reflect Caring Theory in practice more explicitly. The teaching outline for IBD patients reflects the salient issues identified by research participants in the integrative literature review (Appendix E). By addressing issues that are drawn from the patient's perspective, I am demonstrating a respect for the individual and their health experiences which is consistent with Caring Theory in practice.

Goals and Objectives - IBD Support Service

Alberta Health Services (AHS) is currently in the process of redefining the organizational structure and programs offered in the province-wide health system. The mission statement demonstrates the organizational values that overarch the program goals and objectives within the

system. The AHS mission statement is "to provide a patient-focused health system that is accessible and sustainable for all Albertans" (AHS, 2009). This statement is consistent with Caring values and the framework of my practice. In order to align my program goal and objectives with the mission of the organization, I aim to provide a statement that reflects their values and objectives (Appendix F).

In addition to system alignment, the goal and objectives of the GI Support Service reflect the CNA (2008) ANP competencies. The research competency is evident in the service objectives through the integration of a holistic approach, evidence-based practice concepts, and participation in research activities. The leadership competency is depicted in improvements in access to health services and advocacy for treatments and health resources. In addition, leadership characteristics are evident in participation in quality improvement strategies, and sharing knowledge at local, provincial, and national levels. Involvement with the CSGNA will assist me in promoting ANP among colleagues involved in the care of patients with IBD.

The final competency, consultation and collaboration (CNA, 2008), is shown in the language of the goal and objectives for the GI Support Service. Collaborative practice is an essential factor in successful implementation of ANP. My growth as an APN will be determined by my ability to meet the needs of the IBD population and demonstrate effective utilization of the health system resources while optimizing the health status and quality of life for the patients I care for in my practice.

The development of a role description for ANP, goals and objectives of the GI Support Service and an assessment tool for the IBD population based on an integrative literature review serve as the foundation of the practice framework. The teaching outline serves as the basis of developing a mutual care plan and goals for the individuals I care for in my practice. The PEPPA

framework outlines the steps required to introduce the model of care. The next steps are to plan implementation strategies and initiate the APN role (Bryant-Lukosius and DiCenso, 2004).

Future Implementation Strategies

The implementation of the framework for the APN role in my practice will be facilitated by the time I have spent in my current role. The major stakeholders are aware and supportive of the development of the role and my educational efforts. As a first step of introducing my framework, I have prepared a presentation to present at an upcoming GI nurse's conference in which I summarize the findings of my literature review and provide an overview of the lived experience of IBD and quality of life issues for this population. This opportunity will coincide with the completion of my project and provide a starting point to engage in ANP focused on the IBD population.

The next initiative in implementing my practice framework will be to receive endorsement to update my job profile and integrate the new role description. I plan to meet with my supervisor to discuss this aspect of the implementation so that I can promote the advantages of a practice framework and ANP in my role. If successful, I will be laying the groundwork for future ANP roles in my practice setting.

I have begun the process of introducing the practice documents into my current practice. While they are not contingent on establishing an APN role, they will provide documentation for my autonomous practice that can be incorporated into the patients' health records. This is important for continuity of care and for ensuring legal aspects of providing health services is maintained. I will utilize the available resources in my practice setting to develop the forms and produce the documents for the patient assessment and teaching outline.

There are a number of ways that I can evaluate the APN role and model of care. After the first year in my role as Case Manager, I obtained a program evaluation to demonstrate the effectiveness of case management for the IBD population and obtained stakeholder satisfaction levels with the role. This evaluation was conducted with my organization's Research and Evaluation team and included a review of outcomes such as length of stay and reductions in readmissions since the inception of the role. Satisfaction surveys were conducted with feedback from a sample of patients, nursing staff, and physicians with whom I worked closely. This evaluation could be replicated and administered in conjunction with the implementation of the framework and in one year following.

Reflections on the Project

Completing this project has reinforced my decision to focus on the issues faced by people who live with IBD as my population of focus throughout my graduate education. As I read through the literature in the integrative review, I recognized the issues of patients I encounter in my practice and heard their voices through the narratives and research findings. I also recognized the potential impact my role could have on the lives of this population as they live the experiences of illness, healing, and health.

The ANP framework in this project is the result of focusing my attention on the IBD population and ANP throughout my graduate education. The vast majority of my course assignments pertained to an aspect of living with IBD or of ANP in caring for patients with IBD. I was able to apply the knowledge I gained during my program to my practice experiences and reflect on my practice as I developed the competencies of ANP. Although I had been working with the IBD population prior to starting the graduate program, I now feel that I am able to

accurately articulate aspects of their experiences and how I am able to impact their quality of life and overall health.

The documents of the framework are the written foundation of my role. I have established the framework as the theoretical and philosophical foundation of my practice that matches my values and beliefs. The core competencies for ANP will continue to provide a path for the development of my role. As a result of my learning during this project, I find myself more reflective in my daily practice and guided by the knowledge I have gained in this process. I also feel that I am motivated by the accomplishment of completing this framework to continue to pursue knowledge, further develop the framework and promote the ANP role as I engage in developing my expertise in caring for the IBD population. As a result of the experience of completing this project, I have established a path for my future as an APN and as a caring and committed health professional working with the IBD population.

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Appendix A
Literature review – Lived experience of IBD/Quality of Life

Source	Purpose/ problem/background	Sample	Framework	Concepts	Design	Instruments	Results	Strengths/ Weakness	Gaps
1. Banovic, Gilibert, Cosnes, 2008	To assess the impact of Infliximab on subjective quality of life and on the evaluation of state of health	51 consecutive patients with CD	Quantitative comparative	-mode and efficacy of treatment affect QoL	Comparative measures of pts receiving Infliximab and current oral treatment	-Clinical global impression (CGI) -MOS-SF36 -MADRS -HBI	-neither treatment more effective -QoL not affected by mode of treatment -pts overestimate benefits, underestimate risks -adherence improved with infusions, q8week schedule does not affect QoL -depression and active disease affects QoL – perception of efficacy of Infliximab positively affects QoL		Need for long-term studies of treatments and effect on QoL
2. Bovenschen, Laheij, Tan, Witteman, Van Rossum, Jansen, 2004	To study the association between health-related quality of life among patients & presentation of GI symptoms	873 pts referred for endoscopy	Quantitative	-HRQoL and presentation of symptoms	Questionnaire completed before endoscopic procedure	Questionnaire -GI symptoms -EuroQoL5D	-All reported GI symptoms -HRQoL worse in severe symptoms -more symptoms lower HRQoL -UGI symptoms , epigastric pain, bloating, vomiting worsened HRQoL -interference with ADL and essentials of life, pain, altered mood	S-insight into daily life problems for pts with GI symptoms W-co-morbidities not addressed	Need for study specific to symptoms of IBD
3. Childs, 2006	To better explore the decision-making process for determining appropriate nutrition support & explore the issues HCPs need to consider when managing nutrition support	1 Case study	Watson's Theory of Human Caring	-holistic approach to care and goal setting and decision-making -values of respect, reverence, autonomy -understanding fosters healing	Case study	-discussion of case study	-more successful when holistic approach to assessment process -history to include anatomy, weight, intake, output, medications, social -options consider resources, practical issues,	S-applicable to IBD population requiring nutrition support W-no qualitative aspects W-not phenomenological	Not all of Watson's concepts incorporated – Carative factors
4. Clarke and Iphofen, 2008	Explore the lived experience of unseen chronic pain	Convenience sample - 8 pt over 20, under 75 who had attended nurse lead chronic pain clinic & had not attended pain mngt. program	Phenomenology hermeneutic	-HCPs do not believe pain narratives leading to negative effect on self-manage of pain -theme of unseen pain -acute vs chronic	Extended, highly focused low-structured audio taped interview with each pt; pt diaries; & follow-up debriefing interview -textual analysis, coding	-pain diaries -in-depth interviews	Unseen pain: -Isolating effect -withdrawal from enjoyable activities -Invisibility of pain – wishing for obvious signs of pain, illness to develop credibility, wanting to be believed and understood. Lack of clear explanations and diagnosis alters ability to adapt and manage chronic pain. ? in their head, mental illness -Depression – which comes first? Suicidal thoughts and attempts not unusual		Need for further unseen pain narratives

5. Dorrian, Dempster, and Adair, 2009	Examine the relative influence of illness perceptions and coping strategies in explaining adjustment to IBD.	80 adults attending an OP clinic with a diagnosis of Crohn's or UC	Quantitative	-perceptions of ↑severity & symptoms, emotion-focused coping report poorer adjustment, ↑ Treatment & personal control, problem-focused coping report better adjustment , & Coping mediates the relationship between illness perceptions & adjustment	125 adults with IBD, male & female over 18, attending intestinal failure clinic (identified by Surgeon) in OPD over 5 month period.	Questionnaires: -demographic -CDAI -CAI -McGill Pain Quest. -IPQ-R -COPE -IBDQ -HADS -FLP	81 returned questionnaires 64% response rate -33% reported sig levels of psychological distress -29% were absent from work for more than 6 months in the previous year due to IBD -Higher numbers of UC had surgery and ostomies than CD -Perception of more severe disease and cyclical disease course have poorer overall and psychological adjustment -individual coping strategies were not strongly associated with adjustment -behavioural disengagement had higher levels of psychological distress & poorer perceptions of QOL & functional independence -those who understood their condition better were less likely to report psychological distress	S-demonstrates similar levels of psychological distress as other chronic health populations -illness identity & consequences are the most important predictors of adjustment (labels illness) W-quantitative	-more research needed to clarify relationship between illness perceptions and coping.
6. Fletcher and Schneider, 2006	Explore the lived experience of women who had been diagnosed with IBD &or IBS -explores relationship between food and IBS &or IBD	8 females 18-22 with IBD/IBS recruited by on campus posters	Phenomenology qualitative	-coping strategies -relationship between food & IBS &or IBD		Background questionnaires, email interviews, face-to-face interviews	-all reported most significant strategy to cope with condition centred on food consumption or controlling food consumption, eg. identifying & avoiding triggers, diet restrictions, eating healthy, learning about food, stress & food	S-identified life long struggle with food relationship S- gives voice to women	- further studies to identify role of dietary practices & quantification of food and beverages to understand trigger foods
7. Fletcher, Jamieson, Schneider & Harry, 2008	Explore the lived experience of women diagnosed with IBD/IBS with an emphasis on dietary patterns of women before and after diagnosis. Specifically on adverse behaviours women engaged in with respect to food, beverages, medication	8 women with IBD/IBS from a University	Phenomenology qualitative	-lived experience -adverse behaviour related to food, beverages, medications	Critical content analysis Data and investigator triangulation	Background questionnaire 14 day food diary Semi-structured interview	Themes: Engaging in adverse behaviour - dietary restrictions, issues with medications Importance of support Issues with control –controlled by bowels, coping rendered ineffective Implications for practice: Thorough understanding of disease Individualized treatment plan Strong positive respectful relationship between pt and HCP Holistic approach Health diaries, goal setting, detailed health histories	S-insight into under-researched area S-usefulness in practice	Prospective examination of women's behaviour, and men's behaviour to give voice to all

8. Fletcher, Schneider, Van Ravenswaay and Leon, 2008	Explore lived experience of women with GI disorders and strategies for coping with diagnosis.	8 women with IBD/IBS	Phenomenology qualitative	-Diagnosis -Triggers -impact of disease -experiences with HCP -factors associated with coping	Background questionnaire, email & face-to-face interview		Strategies to help with coping - positive attitude, support, controlling situation & surroundings, distraction, relaxation, education and knowledge.		
9. Hall, Rubin, Hungin & Dougall, 2007	To assess patients' perspectives and beliefs about their medication & to determine how this relates to medicine taking & other health related behaviour	31/58 people with established IBD >2years & scored in lowest ¼ of QoL measures in previous study	Grounded theory qualitative	-health-related normalcy -medication -non-adherence -quality of life -perspectives and beliefs regarding medications	-individual interviews -focus groups -additional comments from participants	QSR NUD*IST software	Medication Narratives: -acceptance & perceived necessity (linked to acceptance of illness, changes over time) -fears and concerns – steroids, surgery, more drugs (linked to delays in seeking care) -perceived impact – balance between taking meds and return of symptoms -willingness to self-manage – 2/3 keen to self-manage, seek permission from doctor to manage flare-up	S-triangulation of methods and analysis	Need for further perspectives from people from different cultures Need for comparison to those with better QoL, more recent onset of disease, under different care conditions, and with different levels of adherence.
10. Hall, Rubin, Hungin, Dougall & Neely, 2005	To gain a better understanding of the perspectives and experiences of individuals with IBD & a poor quality of life	Purposive sampling of 58/283 pts with established IBD >2years & score in lowest ¼ of QoL measures in previous study	Grounded theory qualitative	-health-related normality -chronic illness	31 participants -focus groups -in-depth individual semi-structured interviews: Perspectives of experiences and understanding of their illness, health care seeking behaviour and medication.	UK-IBDQ QSR NUD*IST software	Themes: Core – “health-related normality” –continued reassessment, fight to maintain, maintaining appearance of. - restricted freedom – body under attack, unpredictable, restriction of activity, bowel movements, and ADL, freedom=normality=health(adjusted to adapt) - coping strategies – psychosocial, physical, behavioural, medical comparisons to previous condition, during flare-ups & remission, to healthy others & to others with IBD - gaining control of disease – uncertainty of role of diet, stress, & need for rest associated with ambiguity of how much control is possible other than meds. - willingness to self-manage -2/3 keen to self-manage, , sense of self-efficacy, not related to improved QoL, persistent efforts to control disease with diet - reluctance to consult physicians - seek permission from doctor to manage flare-up -perceived necessity of medication -wide knowledge range	W- many participants had co-morbid conditions that may affect experiences W-? bias as some had previously completed questionnaire	Need for further perspectives from people from different cultures Need for comparison to those with better QoL, more recent onset of disease, under different care conditions, and with different levels of adherence. Need for further studies related to diagnoses, disease activity, gender, age.

<p>11. Haynes & Watt, 2008</p>	<p>To gain an understanding healthy behaviours in individuals living with debilitating illness</p>	<p>8 participants from Western North and South Carolina – recommended by HCPs with chronic disease diagnosis from 6 months to 74 years, not on disability, 6 working, 2 retired</p>	<p>Phenomenology</p>	<p>-healthy behaviours -resiliency -guilt, courage, hope</p>	<p>Comprehensive health history, 6 Semi-structured interviews Thematic and concept analysis</p>	<p>Questionnaire Literature review</p>	<p>Successful coping : -Spiritual and family support key mechanism to coping -Illness not the focal point of life -Committed to living life successfully -Comparatively things could be worse -Personality make-up and role models key factors in success Concepts: -Spirituality inseparable from physical bodies -Focus/adaptation on others, rather than illness motivating, maintaining self-worth, goal of healthcare to maintain highest level of functioning and optimizing QoL Literature review: -emotional stages of adaptation to chronic illness -perception changes outcomes in chronic illness -maintaining hope critical component of disease -HCP focus on health, positive behaviours, away from illness -empowerment promotes optimal involvement -promotion of support system essential</p>	<p>S- approached from holistic viewpoint</p>	<p>Replication of studies in other populations (IBD) Compare to persons struggling with chronic illness. Continuing education for HCP to discuss issues of spirituality with pts.</p>
<p>12.Hisamatsu, 2007</p>	<p>The role of psychological stress in IBD (relapse for UC) -CRF stimulated by stress & have potential to regulate gut homeostasis -Stress ↑ intestinal mucosa permeability & alter bacteria-host interactions -Acute psychological stress induced cytokine release in inactive UC</p>	<p>(212 patients with UC)</p>	<p>Quantitative prospective study</p>	<p>-?IBD overlap with IBS -IBD course & symptoms influenced by psychological conditions</p>	<p>-260 pts – no bloody diarrhea lasting 1 month -138/160 had relapses in last 3 years</p>	<p>-multiple-choice questionnaires</p>	<p>- 66.2% indicated stress most prominent factor of relapse -Seasonal fluctuation of relapse ?effect of life events (↑ in Dec) - 63.4% with positive psychological stress improved without additional medication or minimal medication, enema/suppository (not a severe relapse) -other factors identified as risk factor for relapse, eg. sleeplessness, physiological distress, excessive eating or drinking</p>	<p>-the designs of the studies were not cohesive, eg. Crohn’s mixed with UC -stress measurement tools are not adequate -sensitivity to stress is individual</p>	<p>- IBS is a global disorder but insufficient scientific studies to demonstrate an association with IBD</p>
<p>13.Irvine (2004)</p>	<p>To identify the issues that are most important to IBD patients, identify barriers for HCPs in meeting needs, & consider new strategies to respond to needs and improve outcomes</p>	<p>? number of patients in clinic interviewed about most prevalent fears in relation to</p>	<p>Literature review, interview of patients in practice</p>	<p>-QoL is worse when disease is severe -physicians and significant others underestimate the type and</p>			<p>Most prevalent fears: -will I have a normal life expectancy -will I be able to have a family, keep a job and do normal daily activities -will my children get IBD? -will I need surgery? -what are my risks of cancer? -how can I know when I will next have a flare?</p>	<p>S-measures of satisfaction &QoL are more important indicators of illness outcome - physicians need to acknowledge and discuss problems of</p>	<p>Tools to measure pt identified concerns</p>

		IBD		severity of problems reported by IBD patients			<ul style="list-style-type: none"> -are there side effects from my medications? -is this the best treatment for me? -can I afford it? <p>Concerns:</p> <ul style="list-style-type: none"> -not being able to participate in sports or recreation -wanting to feel normal (could be worse) -missing school, work, social occasions -insufficient knowledge of disease -need for immediate access for flares -not being able to get help for sexual function concerns 	concern to their patients -significant benefits in treatments related to improved QoL	
14. Jaghult, Larson, Wredling & Kapraali, 2007	To create an education programme, readily available and suitable for new IBD pts, investigate whether the programme can improve QoL	93/116 pts with IBD in remission	Quantitative – experimental Randomized control trial, pilot study to evaluate content of programme	<ul style="list-style-type: none"> -symptom severity strongest predictor of HRQoL -pts in remission have lower scores than general pop. -level of disease-related info insufficient -better informed pts have less anxiety & worry 	Intervention (55) and control (44) groups –concealed randomization 6 dropped out when told they were in control group	<ul style="list-style-type: none"> -Health Index questionnaire -Sense of coherence questionnaire -IBDQ -rating form of IBD pt concerns (RFIPC) 	<p>Pilot study: Content was well suited for IBD pts, number of sessions reduced from 4 to 3 -2 hour sessions.</p> <p>Intervention Group: Multi-professional (nurse, gastroenterologist, dietician & social worker) group-based once a week in evenings. -some improvement immediately after, no significant improvement in HRQoL in group intervention pts -only sig improvement in RFIPC, > at 6 months</p>	W- are questionnaires sensitive enough to measure effects of education programme -some pts not in remission?	-need to combine education programmes with individual support in order to meet actual problems
15. Jamieson, Fletcher & Schneider, 2007	To study the lived experience, in relation to diet , of women who have been diagnosed with IBD &/or IBS	8 women between 18 & 23 years with focus on pre-illness and post-diagnosis dietary patterns of participants	Phenomenology Qualitative		Background questionnaires, food diaries, semistructured interviews		<p>Themes:</p> <ul style="list-style-type: none"> -Engagement in adverse behaviors -Importance of support family & friends -Issues with control <ul style="list-style-type: none"> -timing & awareness of surroundings -giving in to temptations -determination of diet <p>Key elements of determination of diet -</p> <ul style="list-style-type: none"> -the role of physician - variable assistance -experimentation- self-imposed or monitored/prescribed trial-&-error -seeking information- dissatisfaction with assistance from physician - sought from alternative sources and healthcare professionals → generated frustration, confusion, deprivation 	S-diet is a primary behavioral factor readily manipulated by pts with the intent of controlling or minimizing GI distress	Recommendations: -Personal diaries to monitor progress and assist patients in identifying symptom triggers. -detailed pt histories, goal setting, educating and reassuring pts that HCP will assist can support pts in gaining

							-food modifications - adoption of small frequent meals & snacks, elimination/modification based on individual choices & sensitivities, introduction of healthier items into diet, supplements		understanding & control
16. Joshua-Gotlib, Coyne et al (2004)	Evaluate patient-reported outcomes and burden of illness associated with mild to moderate CD in patients treated with 5-ASA derivatives	14,206 pts with CD from US survey databases	Quantitative	-burden of illness -treatment	Questionnaire packets	IBDQ TSQ-C CWAI	-substantial burden of disease in pts who rate their disease mild to moderate, greater morbidity, -treatments not perceived as effective, concern for long-term use -impact on productivity significant, pts with more symptoms and more flares impaired in work productivity	W- cross-sectional design (may not represent general CD population -Pt reporting of severity of CD could be biased-not all variables reported (smoking)	
17. Leong, Lawrance, Ching, Cheung, Fung, Ho, Philpott, Wallace, Sung, 2004	To compare IBD related knowledge, QoL, and use of complementary and alternative medicines and therapies in two contrasting IBD populations. (Hong Kong and Australia)	Consecutive IBD pts 18-75 years were recruited prospectively (162 participated) from the IBD ambulatory clinics of 2 institutions. 81Chinese/81Caucasian	Quantitative – prospective comparative	-IBD -knowledge -QoL -complementary and alternative medicine	Nonparametric statistical methods used for comparison of knowledge score and IBDQ	-Knowledge questionnaire -IBDQ -CDAI -CAI Primary Endpoint – composite knowledge score Secondary Endpoint – IBDQ, use of CAMT & sources of information on IBD	Knowledge – median score significantly higher in Caucasian group than Chinese group, IBD pts in remission similar. Chinese more likely to misidentify type of IBD, occupation did not influence median scores, education level did not influence knowledge, score improved with disease duration in Chinese and positive trend in Caucasian. Chinese had more misconceptions – risks, effects. 71% Chinese and 65% Caucasians identified higher risk of bowel cancer in IBD QoL – significantly higher in Chinese, no difference between remission and disease activity, no correlation with knowledge score CAMT – 1/3 of both pops. had used CAMT, most frequent was Chinese/herbal medicine, followed by acupuncture, chiropractics, reflexology, aromatherapy Chinese believed more in benefit, Caucasians using CAMT had higher knowledge scores. Use was not influenced by type of IBD, disease duration, level of education, or occupation Sources of information – pamphlets, internet, CCA, magazines, journals, books. Members of CCA scored higher in knowledge		Need for culture and language specific educational materials and motivation to improve knowledge by HCPs Societal differences in reasons for use of CAMT
18.Lynch& Spence, 2007	To enable young people to talk about their experiences so that the analysis of their stories could be used to	Purposive sampling 4 participants between 16	Phenomenology Qualitative	How do youth experience living with recently	Purposive sampling, open-ended questions in individual	Semi-structured interviews- face-to-face, tape-recorded			

	inform 7 improve health care	&21 years		diagnosed Crohn disease?	interviews, and thematic analysis of the verbatim transcriptions				
19. Marri, S. & Buchman, A. (2005)	To review literature describing effect IBD has on the continuum of education and employment		Literature review		PubMed search		<p>Effects on education-IBD pts attain same level of education but take longer than general population.</p> <ul style="list-style-type: none"> -Asymptomatic pts were as likely to attain graduate/professional level of education than symptomatic pts -42% of pts missed 2 wks schooling for hospitalization, 57% missed > 2months -long-term educational goals and education performance hindered by severity of disease -professors were indifferent 21% or hostile 8% -53% of schools had resources about chronic illness <p>Effects on employment- do certain jobs pose risks or do pts avoid occupations due to practical restrictions of illness?</p> <ul style="list-style-type: none"> -?physical activity & exposure to open air might be protective -?air-conditioned artificial working environments, indoors, sedentary (twice as likely) or extended/shift work might increase risk of developing IBD (pts might be more attracted to these types of jobs) -lower rates of IBD in southern climates (outside more, more sunlight) -asymptomatic pts employed equal to general population -resulting impact <ul style="list-style-type: none"> -lost productivity -indirect costs (sick leave, early retirements) -postop IBD pts took a median 6 months off work 	No research on education & employment consequences of extra-intestinal manifestations of IBD such as those with PSC who require liver transplant, bowel transplant or TPN	
20. Mussell, Böcker, Nagel & Singer, 2004	To assess the concerns of IBD patients to determine the impact of psychological and disease factors on concerns and other variables of HRQoL	Convenience sample of 72 outpatients with IBD -more pts with CD had longer duration of illness and more in active state	Quantitative	-IBD related concerns -coping with illness -health locus of control -disease variables	-interview for lifetime and concurrent psychiatric disorders -questionnaires	-Freiburg questionnaire on coping with disease -Illness & health locus of control scale -RFIPC -symptom checklist -Freiburg somatic complaint list	<p>Top concerns:</p> <ul style="list-style-type: none"> -effects of medication -having an ostomy bag -being a burden -energy level -loss of bowel control -having surgery -achieving full potential -attractiveness -developing cancer -feelings about the body <p>Depressive coping – irritability, self-pitying, musing,</p>	<p>S- identified need to target psychological interventions on helping pts to develop effective coping</p> <p>W- some measures failed to capture situations and symptoms specific to IBD</p>	-future studies of the association between disease characteristics and psychological distress -examine the role of coping behaviour on long-term outcomes in IBD

							<p>social withdrawal, helplessness, resignation – associated with predictor of psychological distress, self-rated health status, somatic complaints not related to IBD, affects QoL</p> <p>Active problem-solving coping – actively seeking information, undertaking efforts to solve problems, fighting against the disease – associated with more intense concerns, more somatic complaints. Less successful related to limitations of influencing own disease.</p> <p>No association between health locus of control and disease-related concerns</p>	<p>-not able to derive causalities</p> <p>-most pts in remission – limits generalizability</p>	
<p>21. Nicholas, Otley, Smith, Avolio, Munk, & Griffiths, 2007</p>	<p>To understand the lived experience and elements of QoL as depicted by children and adolescents with IBD</p>	<p>80 participants with IBD between 7-19 years</p>	<p>Interpretive ethnography</p>	<p>-impact of illness on self</p> <p>-functional impact</p> <p>-events/ activities of importance - challenges/ obstacles</p> <p>-relationships</p>	<p>Structured In-depth interviews</p> <p>Content analysis</p>		<p>-Concerns related to IBD symptoms and treatment: flare-ups, disruption, hospitalization, limited mobility, food restrictions, embarrassment, exhaustion, malaise, sacrifice</p> <p>Vulnerability and lack of control: uncertainty – daily, in future. Limited control during flare-ups “on-the-edge”, family tensions, intrusions on privacy</p> <p>Perceiving the self negatively and different than peers: not normal, comparison to peers remind them that not normal, difficulty engaging in activities, frustrations, missing activities, difficulty developing peer relationships, withdrawing</p> <p>Benefits of social support: positive influence on coping, experience greater hope, strengthens family relationships, open discussion improves coping</p> <p>Personal resources in coping: illness means of developing personal integrity, hope as means of adjustment, adaptation a challenge to conquer, normalize experiences of IBD, comparison to lessen impact, focus on areas excelling, activities that fit restrictions</p>		

22. Ng, Millard, Lebrun, Howard, 2007	Examine the effects of a low-intensity walking program on QoL in pts with Crohn's	32 pts with Crohn's, mildly active or in remission physical activity <2 times a week	Randomized prospective - experimental	-exercise -quality of life -IBD	Intervention – low-intensity walking 30 minutes, 3 times a week for 3 months Control- maintain habitual physical activity level	IBDQ IBDSI HBI Measured at 1 month intervals	-low intensity exercise does not increase disease activity -as little as 1 month of exercise in mild disease/remission can elicit beneficial effects in QoL, less fatigue, more energy, less worry -control group has increased HBI (BMs) – no effect on QoL -low intensity exercise recommended for pts with Crohn's in remission	W- control subjects may have known of intervention & increased activity -exercise not supervised	-focus future research on IBDQ subscales (symptoms) & investigate effect of exercise on each -focus on pts with more active disease
23. Oxelmark, Magnusson, Löfberg, Hillerås, 2006	To develop an integrated medical and psychological/psychosocial group-based intervention program for IBD pts and evaluate if the program influences pts HRQoL and coping abilities	24 pts with IBD in remission or low activity	Quantitative experimental randomized Evaluative	-HRQoL -sense of coherence	Intervention – 9 weekly sessions, lectures, group therapy, completed questionnaires Control-completed questionnaires Semi-structured interviews	IBDQ Sense of coherence (SOC)	-no significance in IBDQ or SOC before or after intervention, slight improvements in IBDQ/SOC if intervention given shortly after diagnosis -intervention was appreciated –receiving information and meeting other pts with IBD -disappointment in dietary lecture – wanted more assistance	W-did not assess pre-intervention knowledge	
24. Pipe, Kelly, LeBrun et al, 2008	To evaluate relationships among interventions and outcomes of hope, spiritual well-being, quality of life and length of stay in hospitalized patients	48 hospitalized patients across time- admission, discharge, and 6 weeks post discharge	Watson's theory of Human Caring	-Clinical caritas -Transpersonal caring relationship -caring moment or occasion -	Prospective, Longitudinal descriptive. Review of medical records.	Standardized surveys measuring hope, spiritual well-being, function on activities of daily living, & QoL.	-synergies between hope, spiritual well-being, and QoL -documentation indicates knowing pt (transpersonal caring relationship) -listening, being present, offering encouragement impacts pts during hosp and after discharge -depth of caring can be conveyed by touch listening and caring behaviours have been linked to pt safety and prevention -when nurses conscious of meaning of work & how vital their way of being is in health & healing, may provide career satisfaction & significance -psychosocial needs associated with LOS – identify early, construct interventions, make appropriate referrals		
25. Ranjbaran, Keefer, Farhadi, Stepanski, Sedghi & Keshavarzian, 2007	To characterize sleep disturbance in IBD using validated measure of sleep and QoL	119 pts – 80 with inactive IBD, 24 with IBS, 15 healthy controls	Quantitative	-sleep disturbance -course of IBD -QoL	Multisite case control study Positive control group – IBS, Negative control group – healthy	Self-administered mail-in questionnaire pkg– PSQI, IBD-Q	-nocturnal GI symptoms cause poor quality of sleep -IBS does not cause nocturnal symptoms, sleep disturbances common in IBS - sleep disturbances common in IBD, even when inactive, impacts QoL - altered perception of hot/cold - ?abnormal sleep patterns -IBD prolonged sleep latency, IBD used more sleep aids than IBS	S-first study to characterize sleep disturbances in IBD W-small sample size, exclusively self-reported measures, retrospective	-Explore whether fatigue is result of poor sleep or other causes

<p>26. Sainsbury & Heatley, 2004</p>	<p>To review psychosocial factors affecting QoL in patients with IBD</p>	<p>107 articles</p>	<p>Literature Review</p>	<p>-QoL</p>			<p>Gender – females have poorer QoL, rate symptoms more severe, more extensive disease Socioeconomic status - ↑morbidity, ↓QoL in lower SE class, SE levels of IBD pts =>background pop Ethnicity & Culture – QoL scores ↓in black pts despite similar disease process Age – onset in adolescence may lead to psychological morbidity, elderly lack supportive social networks, elderly more refractive to treatments Knowledge - ↓QoL in lower education levels. Reported insufficient IBD education – limited benefit Personality traits – poor post-op QoL associated with anxiety & poor socialization Psychological factors – effect of stress on gut motility, visceral sensation, ?immune regulation, health-seeking behaviour Perceived stress – perception that stress precipitates onset or relapse Coping strategies – effective coping + correlation with QoL, maladaptive coping neg. Correlation with QoL Psychotherapy – none provided evidence of benefit Self-image/sexuality – significant factors in QoL, ↑freq of BM, urgency, incontinence, body image, fistula, stoma Social circumstances – conflicting evidence on marriage, divorce in IBD pop, CD have slightly fewer children, higher infertility rates. Social network support high and positively influences QoL-support groups limited interest Smoking – risk factor for development and exacerbation of CD (↓QoL, ↑disease activity), patches reduce disease activity in UC Attitudes to pts with IBD – shared decision making - ↑QoL, 30% conceal disease from employers, viewed in negative light by insurers</p>	<p>W- participation rates suboptimal (reluctant to discuss) Self-selected respondents Questionnaires have short-comings – long, ? reflective of QoL</p>	<p>Insufficient studies related to QoL and self-image/sexuality Little published on effect of HCP attitudes toward pts with IBD</p>

27. Savard & Woodgate, 2008	To arrive at an understanding of the lived experiences of young persons with IBD and an ostomy	6 young adults (19-24) with IBD who had an ostomy	Phenomenology -hermeneutic	-experience of living with IBD and a temporary ostomy	12 open-ended in-depth interviews	transcripts	Themes: “concealing and revealing self” Uneasy feelings – embarrassment, feeling different, frustration, worry, why me? It’s hard – restrictions, unpredictability/loss of control Renewed sense of self – freedom, new lease on life	S-revealed areas where nurses can intervene in practice, restrictions, unpredictability/loss of control, pain. Need for social support identified W-Retrospective design (data from memories), one point in time	Pain has not been adequately studied in qualitative studies for IBD population Need for more studies of males and other ethnicities, permanent ostomies
28. Schneider & Fletcher, 2008	To describe the negative impact of IBS & IBD upon university-aged women.		Phenomenology Qualitative			Email and semistructured interview	-anxiety reaction -anatomy of an attack -cascade of impact -emotional effects: helplessness, embarrassment, guilt -physical effects: fatigue and pain -limitations on food and social activity	-use daily diary to discuss issues and track triggers & attacks -patient handbook -plan of action -support network -investigations -coping strategies	
29. Visschers, Olde Damink, et al (2008)	To investigate the long-term HRQL of patients treated for Enterocutaneous Fistula compared 2 healthy controls	65/135 pts with ECF between 1990 & 2005			Retrospective database	Karnofsky performance scale (KPS), short form 36 (SF-36) & IBDQ		W- retrospective therefore susceptible to selection & information bias	
30. Wolfe & Sirois (2008)	Examine IBD pts subjective experience of daily impact of IBD & categorize dimensions of HRQoL using the pts own voice.	282 pts with IBD Mainly Caucasian female with CD	Qualitative	“How has IBD affected your daily activities?” -Do SF-36 and IBDQ measures represent the experiences of pts and give them a voice?	Secondary analysis of study examining the well-being of people living with IBD.	Online or paper survey by mail. Data submitted electronically & anonymously.	6 broad dimensions of HRQoL: -physical (systemic functioning, energy/vitality, pain) Both +ve & -ve -emotional anxiety, depression, fear, loss of passion -social lack of understanding, value of experience, acceptance -cognitive (functioning & attending to disease) motivation, alertness, disposition, self-image, worry, planning around -self-regulatory (taking control, loss of control, neutral) I am, I plan, effectively deal with, I never, I do not, I can’t, I have to, I need to, I feel -practical insurance, work, finances, loss of time -Not all people frame disease from negative point of view	S- identified concerns not addressed through IBD QoL measures -identified seeking to gain control is linked to self-efficacy (positive changes as a result of IBD better eating & exercise habits) -identified limitations of quantitative surveys and need for narrative data to	-HRQoL tools for IBD do not measure cognitive dimensions, little attention to practical concerns, self-regulation

									identify other dimensions of HRQoL.	
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Appendix B

Examination of Nurse-led Programs

Program	Nature	APN preparation	Focus	APN role	Frameworks – theoretical/ philosophical	Best Practices	Important aspects of nurse/patient relationship
Palliative Care	Inpatient consultation service Shared Leadership Model	MN, expertise in area of practice	Clinical, education, research, and administration	Clinical consultation with patients and families, in person and by telephone	Paterson and Zderad humanistic nursing theory and concepts of relational practice, Postmodern perspectives	Pallium Palliative pocketbook. Guidelines from www.chpsa.net	Caring presence, relational practice
IBD Clinic Nurse	Primarily Clinic, some interaction with hospital inpatients, and endoscopy	MN, Advanced practice in pediatric GI	Outpatient IBD assessment, education, followup, referral to clinical trials	Liaison between patients and gastroenterologists, in person, by telephone and facilitates emergency visits and admission to hospital	No identified framework Practice documents – Job description	No formal best practice documents	Patient advocacy
Enterostomal Therapy Nurse Consultant	Acute, community, continuing care	MN, MEd, clinical specialization in are of practice, certificate in ET therapy	Consultation service to address wound care and ostomy needs,	Consultative clinical care in person, by phone and email, staff & client education, develop of policies and procedures incorporating best practice in ostomy and wound care	Model for wound and ostomy care Incorporates aspects of a number of perspectives Appreciation for person's learning style and capacity, right to choice, informed choice, collaboration, respect	RNAO best practice guidelines, NPUAP, CAWC, CAET Guidelines for wound and ostomy care	Continuity of care

Appendix C

ROLE DESCRIPTION CASE MANAGER – Specialty service

SCOPE OF PRACTICE:

- 1) Collaborates with Specialists regarding care of inpatient and outpatient population.
- 2) Role is to act as a central member of a multidisciplinary team with specific responsibilities related to:
 - Comprehensive and holistic assessment of patients under the care of the Specialists
 - Participate in the day to day management of this patient population
 - Communicate and coordinate with the team to facilitate investigations, treatment and discharge needs
 - Apply knowledge of pathophysiology and therapeutics in completion of histories and physical assessments as they pertain to patients admitted under the care of the Specialists
 - In collaboration with and under the direction of the-Specialists, the Case Manager is responsible for performing and dictating assessments, obtaining histories, performing certain interventions, and arranging referrals as well as managing patient care for this selected population

QUALIFICATIONS:

Case Manager:

- Baccalaureate degree in nursing accompanied by recognized certificates in Specialty or, diploma in nursing accompanied by Canadian Nurse's Association Certification in nursing specialty and registration in a Post Diploma Baccalaureate program.
- Extensive background in the inpatient and outpatient setting providing consistent support for physicians undertaking a variety of investigations and therapeutics for patient population.

Case Manager-Advanced Practice:

- Graduate (Master's) degree in nursing and Canadian Nurse's Association (CNA) Certification in nursing specialty as stipulated by the CNA.
- Advanced level of clinical nursing practice that integrates graduate educational preparation with in-depth nursing knowledge and expertise in the field of Specialty.

REPORTING:

The Case Manager - specialty and Case Manager - Advanced Practice - specialty report jointly to:

- Department Director
- Appropriate physician specialists

RESPONSIBILITIES:

Case Manager - Specialty

- Comprehensive health assessment based on thorough history and physical exam
- Identify health care issues and develop an in-depth plan of care in collaboration with the patient and family, physician specialists and any other identified members of the interdisciplinary team
- Support the appropriate and timely access to specific diagnostic investigations, therapeutic interventions and health resources
- Upon collaboration with the physician specialists receive and document orders for selected diagnostic procedures and therapeutic interventions

- Provide in-depth education and counseling to patients and families related to the medical management and experience of living with health issues that occur in this population
- Document/dictate admission histories, plans of care, diagnostic investigations, procedures, response to interventions, summary of hospitalizations and discharge plans
- Act as a resource to inpatient nursing departments as well as outpatient nursing departments
- Participate in quality improvement initiatives and risk management activities by attending reviews of patient care issues and attending various workshops or conferences as offered
- Demonstrate leadership skills, expertise, accountability, in-depth knowledge, and teaching skills consistent with scope of practice
- Participate in development, implementation and evaluation of policies and procedures related to standards of care for nursing practice
- Support and participate in research activities to enhance evidence-based practice in the nursing specialty

Case Manager - Advanced Practice, Specialty

In addition to the responsibilities of the Case Manager, the Case Manager - Advanced Practice, Specialty will meet the competencies and demonstrate the characteristics of Advanced Nursing Practice as described by the CNA (2008). This will be accomplished through maximal integration of graduate educational preparation, in-depth nursing knowledge and clinical expertise in specialty area of clinical nursing to:

- Provide and ensure efficient and effective care to specific patient population with a high degree of autonomy
- Demonstrate leadership and initiative to improve patient outcomes, and influence organizational and system change for this population
- Integrate in-depth nursing knowledge, research and clinical experience along with interdisciplinary knowledge
- Improve access and quality of care to the patient population by implementing a wide range of strategies based on a depth and breadth of knowledge
- Ability to articulate and apply the theoretical, empirical, ethical and experiential foundations of nursing practice
- Utilize knowledge to understand, develop and disseminate evidence-based nursing knowledge in the form of practice guidelines, patient information material, patient and colleague education
- Initiate or participate in planning, coordinating, implementing, and evaluating programs to meet the needs of the patient population and support nursing practice
- Utilize knowledge-transfer techniques to apply research-based knowledge in practice
- Demonstrate advanced judgment and decision-making skills
- Critically examine and influence health policy that impacts patient population

STATUS:

- FTE: 1.0, Monday through Friday
- Hours of work – determined by population need.

Appendix D
Inflammatory Bowel Disease Support Service
Health and Illness Assessment
& Plan of Care

Purpose: This assessment and care-planning tool provides a baseline for developing a comprehensive picture of the health and illness experiences of patients with IBD. When used in conjunction with a caring and holistic approach to care, the tool can contribute to the development of a transpersonal caring relationship between the health care provider and patient. This is accomplished by focusing on the patient's lived experiences of IBD and incorporating mutually developed strategies to promote healing and health.

Date of encounter _____ face-to-face telephone
Referred by Gastroenterologist _____ GP _____ **for** _____
Patient's primary concern (s) _____
Allergies _____
Weight _____ kg **Ideal weight** _____ kg **Height** _____ cm **BMI** _____

IBD health/illness experience

Crohn's Ulcerative colitis _____ Indeterminate _____
 Date of diagnosis _____
 Age at onset of symptoms _____ years
Extent of disease rectum colon - Right - Left Ileum duodenal
 gastric esophagus/mouth extra intestinal _____
Symptoms at onset diarrhea rectal bleeding abd pain/cramping fatigue
 weight loss fistula drainage other _____
 frequency of flare _____ last flare _____

IBD Treatment since diagnosis (name, dose and dates, concerns)

5-ASA _____
 corticosteroids _____
 immunosuppressant _____
 biologic _____
 antibiotics _____
 opiates _____
 NSAIDS _____
 anti-diarrheal _____
 investigational _____
 other _____

Surgery (location, extent, date, surgeon, complications)

Hospitalization experiences _____

Current HRQoL issues

Bowel movements **HBI** _____ **Number of liquid stools per day**
 diarrhea watery loose formed ostomy ileal-anal pouch
 rectal bleeding _____ (describe)
 urgency nocturnal incontinence tenesmus steatorrhea fissures fistula
Pain/GI concerns **HBI** _____ **0-none, 1-mild, 2- moderate, 3-severe**
 location _____
 nature/frequency _____
 bloating nausea vomiting decreased appetite weight loss/gain _____ kg
Abdominal Mass HBI _____ **0-none, 1-dubious, 2-definite, 3-definite and tender**
 fever night sweats
Other manifestations **HBI** _____ **Score 1 per item**
 arthralgia uveitis erythema nodosum aphthous ulcers

pyoderma gangrenosum
anal fissure new fistula abscess _____

Well-being/lifestyle

HBI _____ **0-very well, 1- slightly below par, 2-poor, 3-very poor, 4-terrible**

fatigue depression stress sleep nutritional concerns employment concerns
financial concerns housing concerns relationship concerns
sexual function/fertility concerns pregnancy/breastfeeding concerns
language barriers other fears/concerns

_____(describe)

Social/Spiritual (identify strengths and concerns from patient perspective)

smoker _____ alcohol _____ recreational drug use _____
exercise _____ recreation/hobbies _____
supports _____ education _____
spiritual beliefs _____ insurance _____
employment _____ community services _____
annual pap/prostateexam/mammogram _____
other _____

Total HBI _____

Additional health/illness experiences

other conditions _____
injuries _____

Family illness IBD _____

Cancer Arthritis IDDM Celiac CAD HTN Asthma TB

Investigations (most recent)

Endoscopic _____ date _____

Biopsy results _____

Imaging _____ location/date(s)

abdominal ultrasound barium studies CT scan MRI abd/MRCP

bone density CXR other _____

Laboratory _____ name of laboratory _____

routine/scheduled _____ celiac hepatitis serology

ANA/anti-DNA

Immunizations - up-to-date

DPT-P MMR Hepatitis A Hepatitis B Chicken pox

HPV meningitis Pneumovax [] Flu vaccine

Mantoux _____ mm _____ date

Travel vaccines

Current Medications – name, dose, schedule, duration, last dose

5-ASA _____

Corticosteroids _____

Antibiotics _____

Immunosuppressant _____

Biologic _____

Prescribed for other conditions _____

Herbal/natural _____

Vitamins _____

Over-the-counter _____

Nutritional supplements _____

Current Coping & Self-Regulation Strategies

Plan-Coping and Self-regulation Strategies (discussed and developed with patient)

Identify needs with patient for health diary, education, exercise program, dietary alterations, treatment/reimbursement assistance, referral to additional resources, follow-up, monitoring, support, etc.

Patient identified priorities:

Patient identified goals:

Follow-up plan and timeline:

Date/Time

Signature

Appendix E

Teaching Outline for Inflammatory Bowel Disease

Pt requests information	Identified from health/illness assessment	Written Material	Discussion	Review/plan
	Disease process: -Crohn's disease -Ulcerative Colitis			
	Treatment: -oral -enteral -parenteral			
	Nutrition: -oral -enteral -parenteral -alterations			
	Investigations: -endoscopy -laboratory -diagnostic imaging			
	Social: -family -employment/school -fertility/pregnancy			
	Financial: -income assistance -insurance			
	Community support: -family -CCFC			
	HRQoL issues			
	Other			

Appendix F

Gastroenterology (GI) Support Service

Goals and Objectives

The goal of the GI Support Service is to provide a patient-centered caring Advanced Nursing Practice (ANP) program across the health system continuum. The Advanced Practice Nurse (ANP) supports the patient population living with Inflammatory Bowel Disease in collaboration with and complementary to the services provided by the Gastroenterologists in the Central Alberta zone of Alberta Health Services.

Objectives:

1. To improve communication of patient needs by timely and comprehensive assessment of patients' health status when entering the health continuum through the Emergency and Endoscopy departments and from the Gastroenterologists' offices.
2. To facilitate access to investigations and health services through collaboration with other health care providers and programs, and coordination of appropriate preparations for diagnostic investigations.
3. To provide a holistic approach to ANP that integrates theoretical, ethical and evidence-based practice concepts and values that assures respect for the health and illness experiences of the IBD patient population and an environment that promotes health and healing through a caring and consistent approach.
4. To develop a therapeutic transpersonal caring relationship and health-promoting focus with the patients living with IBD who require acute, ongoing and intermittent access to health services for treatment of their illness.
5. To support patients who live with IBD to develop their capacity for self-efficacy and maintain optimal quality of life through education, support and advocacy for treatments and health system resources.
6. To participate in research activities, quality improvement strategies, development and sharing of IBD and ANP knowledge at the local, provincial, and national levels.
7. To consult and collaborate with health care providers across sectors and at all levels of the health system to promote the contributions of ANP in an inter-disciplinary health team.