

## Specialist Nursing Interventions for Inflammatory Bowel Disease

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**Received:** January 09, 2019; **Published:** January 31, 2019

### Abstract

**Background:** Inflammatory bowel disease (IBD) refers to a group of diseases that is characterized by chronic inflammation of the digestive system.

**Aim:** The aim of the present study was to discuss the available scientific evidence on the quality of care in IBD, in relation to nurses.

**Methodology:** A PubMed and Cochrane literature search was performed using the search terms 'reproduction' and 'inflammatory bowel disease' and using the headers and main subjects of each section of this article as search terms.

**Results:** Specialist nurses, which have been increased in recent years, should be part of the multidisciplinary team for IBD patients. Nursing interventions for many of the complications and symptoms of patients with IBD should focus on the knowledge of the person and the environmental factors. A challenge for IBD nurses is to provide evidence supporting the relevance of their role in caring IBD patients.

**Conclusion:** The concept of nurse-IBD clinics needs to be explored in greater detail. Development of new roles might be a way of making the career of nursing more attractive, extending career pathways. The changes taking place improve the quality of healthcare services in gastroenterology. The future of gastroenterology depends on the collaboration work.

**Keywords:** Inflammatory Bowel Disease (IBD); Chronic Disease; Nurses; Nurse's Role; Nursing Interventions; Quality Indicators; Quality of Life

### Abbreviations

IBD: Inflammatory Bowel Disease; UC: Ulcerative Colitis; CD: Crohn's Disease; HRTI: Human Response to Illness Model; SGNA: Society of Gastroenterology Nurses and Associates; CSGNA: Canadian Society of Gastroenterology Nurses and Associates

### Introduction

Inflammatory bowel disease (IBD) refers to a group of diseases that is characterized by chronic inflammation of the digestive system. Ulcerative colitis (UC) and Crohn's disease (CD) encompasses the most common forms of chronic IBDs. Our current knowledge suggests that the etiology may be multifactorial and is thought to be triggered by interactions between various environmental, genetic and immunologic factors. Recent studies show an increasing rate of IBD in several developing countries (Africa, South America and Asia). Western

countries have an increased incidence of ulcerative colitis together with CD, due to their life style and the contemporary way of life in general [1,2].

Like any other chronic illness, IBD may have detrimental effects on the individual involved as well as his/hers immediate family and social circle. Given the complexity and sometimes subtle signs of the disease, it often may take significant time and effort to make the correct diagnosis. However due to new technological developments and increased awareness on the condition, and with specialized centers, the diagnosis can now be easily made with less time and effort. IBD is a disease that entails time and high laboratory diagnosis difficulty [3]. IBD generally affects young people in their productive years and has a negative impact on the quality of life [4]. The impact of IBD on physical and mental health, social well-being, and economic stability of patients and their families is highly variable although any patients develop depression and anxiety as well as diseases related disability [5]. The daily activities of this group of patients are affected particularly secondary to the symptomatology which includes abdominal pain, fatigue and diarrhea. The emergence of IBD in recent years especially in young people, has affected not only the patient but his/her entire family. Challenges with self-management skills, continue beyond adolescence into emerging adulthood and targeted interventions in the adult gastroenterology clinics should be undertaken, enhancing the educational role of gastroenterology nurses [6,7].

IBD is a life-long incurable illness which requires chronic medications. It causes flares of acute intestinal inflammation, associated with bloody diarrhea, abdominal pain and as a result patients remain at home so as to avoid public toilets. Fecal incontinence is a devastating social and hygiene problem, impacting heavily on quality of life and impacts on their ability to work and socialize. Patients with IBD, have a high incidence of incontinence. The chronic and relapsing nature of IBD and the potential need for medical or surgical interventions raise concerns about family planning issues. IBD produces high costs in health systems, due to the medical-surgical hospitalizations [8]. According to epidemiologic and population studies, several factors may be contributing to the etiopathogenesis of IBD: Infectious diseases, diet, nutrition during infancy, refrigeration of food, low socioeconomic status, use of nonsteroidal anti-inflammatory medications and antibiotics, smoking and psychological disturbances [9].

Health care providers who specialize in the treatment and management of inflammatory bowel diseases, are equipped with specialized knowledge and expertise, thus they should be able to accomplish their therapeutic goals. Some of these clinical targets can induce rapid remission, improvement in the patient's quality of life, avoidance of surgeries and reduction in the admission rates. Once these targets are met, mortality and morbidity that are directly related to the diseases, are significantly reduced [9,10]. The healthcare professional who specializes in IBD knows how to deal with those patients. Therapeutic goals for treating IBD include improving quality of life and inducing rapid remission, maintaining clinical remission, avoiding surgery and reducing hospitalizations, as well as preventing mortality due to the disease [11]. As in all chronic illnesses, it is considered as a given to have personalized care for each patient regardless of the underlying diseases. However, the patient's support through the multidisciplinary approach is just as important for the patient with IBD, due to the fact that there are many complicated factors which need to be coordinated by the team [12].

IBD management requires a multidisciplinary approach in which physicians, nurses, social workers work together. Among the professionals involved in therapy of IBD, nurses play an important role. The purpose of quality of care programs is to improve patient outcomes. Among the patients' outcomes are clinical outcomes, quality of life and patient satisfaction. In this article will discuss the available scientific evidence on the quality of care in IBD, in relation to nurses [13]. The systematic review provides a synthesis of the available evidence on relevant aspects of the quality of care in nurses' management of IBD.

## Methods

A PubMed and Cochrane literature search was performed using the search terms 'reproduction' and 'inflammatory bowel disease' and using the headers and main subjects of each section of this article as search terms. The inclusion criteria were:

1. Documents referring IBD.
2. Documents with information about the involvement of nurses in the management of IBD (Nursing interventions in IBD).

A systematic research of bibliographic databases was performed with regard to management of IBD by nurses. The key words used the following medical subject headings: Inflammatory bowel disease, chronic disease, nurses, nurse's role, nursing interventions, quality indicators, quality of life. The search was limited to files-documents written in English.

## Results and Discussion

IBD has a characteristic symptom, such as diarrhea abdominal pain among others. These symptoms can be particularly distressing to an individual with IBD and is often manifested by fear and anxiety. A comprehensive understanding of the physiology, pathophysiology, behavioral and experiential perspectives of diarrhea would facilitate the provision of holistic nursing care to IBD patients and their families. The symptom of diarrhea can be a great nuisance to the person with IBD. Although the exact reason-etiology of IBD is still unknown, interactions between mucosal immunity and intestinal microflora are probably the main factors. One basic intervention is the use of probiotics which alter the bacterial composition and doing the environment unfavorable to pathogenic organisms. By understanding the physiological, pathophysiological and behavioral perspectives, the Human Response to Illness model (HRTI) guides nursing interventions to assist individuals cope better with their condition. The HRTI model encompasses all these concepts, thereby enabling the development of a quality care plan for these patients. Recently, probiotics have been discussed as an alternative and complimentary therapy to the commonly used pharmacological treatments. The HRTI model enables the nurse to achieve a comprehensive understanding of all perspectives of this human response to IBD. This holistic approach will establish the rationale for alternative therapies, such as probiotics and as the basis for evaluating nursing care. With the HRTI model we can discuss the nursing implications of this alternative therapy with probiotics [9,13].

Within the HRTI framework, nursing interventions for diarrhea related to IBD should focus on the knowledge of the person and the environmental factors. Using this knowledge, appropriate therapies can be developed. It is essential for nurses who involved in the care of patients with diarrhea related to IBD, to understand the reasons of diarrhea. By using the HRTI model nurses are able to address the emotions of fear, uncertainty that often described in patients with diarrhea. The knowledge that stress can play an important role in diarrhea, nurses helps the patients to develop effective stress management techniques. In addition, patient education has beneficial response to illness [13]. Nurses play an important role in the management of IBD. The use of HRTI model provides a holistic and quality nursing care [9]. Another symptom in patients with IBD is fatigue. Several studies have identified fatigue as one of the leading concerns for people with IBD. A recent systematic review and a randomized controlled trial in IBD patients identified that fatigue prevalence ranges from 41% to 48% when disease is in remission, to 86% when it is active [14,15].

The aim of the review reported is to establish how the healthcare professionals manage these symptoms better so as to improve patients' quality of life. The reviewed literature offers incomplete information as to the causes, the ways of treatment. Methods of managing fatigue must be further explored. The multidimensional nature of fatigue needs the combination of different approaches. In this area, nurses may play an important role. Managing patients with IBD, requires a multidisciplinary approach using the expertise of doctors, nurses, dieticians, social workers. The literature shows the emergence of the nurse specialist in IBD. Nurses provide education, counseling, support to patients [9,16].

The Canadian Nurses Association indicated the patients' central role in the management of IBD. Registered nurses (RNs) play an important role in IBD therapy. The attributes of nurses most highly valued by patients and their families include availability, kindness, empathy, ability to communicate and increase patient's confidence [7].

In one intervention study, patients received educational material on lifestyle, health promotion, medications. Direct telephone access to the specialist nurse was established. The outcome of the study was patient's health status, hospital admissions, length of stay, quality of life, satisfaction with management of IBD. The results are: hospital visits were reduced by 38% and length of hospital stay by 19%. Quality of life was unchanged. Patient satisfaction improved [17]. The IBD nurse specialist is a valuable member of the gastroenterology team,

due to improve patient education and disease therapy/outcomes. In one opinion article [18], has discussed the importance of support IBD patients with specialist IBD nurses. Nurses have a basic role in the coordination of support groups for these patients. Outcomes of the article were: quality of life, wellbeing, levels of stress and anxiety.

In observational study conducted at 8 university hospitals and 4 general hospitals, were compared European health care facilities and was defined best practice in IBD management [19]. The best practice related to nursing interventions is: availability of telephone consultation, continuous postgraduate training and rotation in outpatient, inpatient and endoscopic unit. In another observational study, including 825 patients with IBD, showed a high level of satisfaction with the service, especially with the psychological support [20]. The nurses are responsible for a telephone helpline, hematological monitoring and follow-up [13].

Specialist nurses should be part of the multidisciplinary team for IBD patients. They are essentials as the point of contact between patients and health professionals. According to the standards of clinical nursing practice and role delineation statements, published by the Society of Gastroenterology Nurses and Associates (SGNA), 16 functions carried out by specialist nurses. Nurses must evaluate their own professional practice, establish priorities, collaborate with other professionals, manage follow-up of patient care. These standards help to develop quality clinical nursing practice in gastroenterology, based on the standards of the American Nursing Association [21,22]. In a qualitative study, including 3 patient groups with IBD, develops quality criteria for the management of four gastrointestinal disorders, IBD, celiac disease, irritable bowel syndrome, gastroesophageal reflux disease [23].

The IBD Standards Group, determine the service standards for the healthcare of people who have inflammatory bowel disease. The document describes the standards so as IBD patients receive high quality care. An IBD unit that serves a population with 250,000 should have 1, 5 specialist nurses. Patients should have rapid access to clinical counseling from specialist nurses, by telephone or email. Also, nurses must participate in meetings of the gastroenterology team for IBD patients [7]. The number of IBD specialist nurses has increased in recent years. The study suggests the need to increase the number of specialist nurses to the level recommended by the IBD standards Group. Access to telephone contact with an IBD specialist nurse is available in 85% of sites and email is available in 41% of sites [24]. The Canadian Inflammatory Bowel Disease Nurse's Survey was developed and was targeted at GI nurses, who have a role in caring patients with IBD. In collaboration with the Canadian Society of Gastroenterology Nurses and Associates (CSGNA), and the Canadian Association of Gastroenterology (CAG), the survey was circulated via email, so as to examine the role of IBD nurses and nursing services provided in Canada. The study cohort was characterized using standard statistics. For continuous variables, ANOVA was used to test for differences among the nursing groups. The survey generated feedback from 275 nurses. Of the 275 nurses, 90% reported that they worked with IBD patients, only 28% indicated that their primary nursing role was in IBD care [24]. A total of 118 nurses were working in endoscopy units. This unit is essential to nursing interventions in IBD patients, the roles are well defined within the nursing community. Further analysis of nurses, who worked in IBD care, showed that 79% worked with the adult population, 10% worked with the pediatric population and 10% worked with both adult and pediatric patients IBD. IBD research nurses coordinators represented 16, 5% of respondents. These nurses provide clinical care; confirm accuracy of data collection, guaranteeing the integrity of protocol implementation [24].

All services-nursing interventions, such as telephone advice line, rapid access clinics, are offered. Most IBD nurses devoted clinical time to the outpatient setting (39%), inpatient care represented only 8, 6%. Nurses devoted 44% of their time providing telephone advice [7]. The majority of the nurses (92%) worked with adults. There was variation among job titles in those surveyed. Some nurses also worked outside in cardiology, oncology and dermatology. A challenge for IBD nurses in Canada is to provide evidence supporting the relevance of their role in caring IBD patients. The concept of nurse-IBD clinics needs to be explored in greater detail. With ongoing growth and expansion of the nurse specialist role in Canada, further development of services such as: telephone helplines, outpatients clinics, biologic, rapid access clinic, could be possible. Further development of IBD nursing roles was addressed, together with the need for learning opportunities and networking with other nurses. Further exploration into specific nursing services in Canada, educational preparation, scope of nursing practice, responsibilities of IBD nurses is still required [24].

In recent years, the multidisciplinary approach of patients with IBD focuses on detecting problems that arise not only from organic events but also often involving psychosomatic events. Quality of life measurements are often utilized in patients with IBD. Sexual health is one of the measurements which play a significant role in patients with chronic illness. Sexual dysfunction has been determined to be one of the main parameters found in many surveys [25]. Despite the fact that in some patients this issue may or may not play an important role in their lives, what actually happens with regards to sexual dysfunction at a particular moment in their lives can give significant conclusions about that individual [26,27]. Through a systematic review, studies on the issue of sexual dysfunction in patients with IBD have demonstrated that women most often report a problem in their sexual lives coupled with anxiety, and co-morbidity, as well as the age of the patient, developing a vicious cycle that complicates their situation. Patients are also very concerned about their sexual lives, due to the negative body image. While the difference in the sexual function of patients is significant, with IBD the situation gets even worse after any operation regardless the nature of the procedure, i.e. stoma placement or not [27-29].

Detecting sexual dysfunction is a difficult process for the health scientist, and this will be accomplished through a spherical approach of the patient. In order for the patient to express his/her sexual complaints, a good relationship with the entire IBD team has to be established. A bond based on trust is of critical importance in allowing the patient to freely express his or her concerns in this very private matter. In this particular group of patients, the role of the nurse is extremely important with regards to continuous education and monitoring his/her progress. It becomes obvious that with a good nurse-patient relationship, given the fact that a good nursing record is available, the treating nurse will have a better understanding of the patient's underlying sexual dysfunction [28,29].

In conclusion, in order to achieve all the therapeutic goals in patients with IBD as well as achieving optimal management of these patients, they should be managed by the multidisciplinary approach which includes IBD specialists, a nurse specialist, a psychologist as well as a nutritionist. Despite the difficulties in the health care systems, such as staff shortages, specialization in this type of illness, offers a safety valve so as to be able to provide the best possible integrated care with the best outcomes.

### Conclusions

Nurses are often regarded as a lower part of the health care pyramid. Creaming off the best nurses into new roles may improve outpatient nursing service and the management of several chronic disorders, such as IBD. Despite ongoing continuing knowledge and education, management of these particular groups of patients with IBD remains a challenge. There are many hurdles that we as healthcare professionals have to overcome in order to improve the patient's outcomes. It is without a doubt that through the multidisciplinary approach one will be able to give the best possible care.

Development of new roles might be a way of making the career of nursing more attractive, extending career pathways. The health service of the future will comprise an integrated workforce of multidisciplinary teams. The changes taking place improve the quality of healthcare services in gastroenterology. The future of gastroenterology depends on the collaboration work.

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**Volume 6 Issue 2 February 2019**

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