

# **Nursing Care for Inflammatory Bowel Disease: Patient Support and Symptom Management – A Scoping Review**

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### **Abstract**

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This research presents a scoping review focused on the role of nursing care in managing Inflammatory Bowel Disease (IBD), specifically Crohn's Disease and Ulcerative Colitis. The study aims to synthesize evidence on nursing interventions that enhance patient outcomes and quality of life. Twenty primary studies were analyzed through a rigorous selection process, highlighting the significance of specialized IBD nurses' educational support, counseling, symptom management strategies, etc.

The findings underscore the critical need for comprehensive patient education to empower individuals to manage their conditions effectively. Awareness sessions and training modules are recommended to prepare patients for potential complications associated with IBD. The research also identifies limitations, including a narrow focus on nursing perspectives.

The study provides valuable insights into the qualitative aspects of nursing care, emphasizing the importance of a collaborative approach among healthcare professionals. The thematic analysis reveals common strategies that can be employed to improve symptom management and overall patient well-being. This research contributes to the growing body of knowledge on IBD nursing practices and is a foundation for future studies to enhance care delivery in this complex field. Ultimately, the recommendations aim to foster a more informed patient population and a more integrated healthcare approach to IBD management.

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Language: English

Key Words: Inflammatory Bowel Disease (IBD), Crohn's Disease, Ulcerative Colitis, Nursing Care, Patient Education, Symptom Management.

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# 1 Introduction

Inflammatory Bowel Disease (IBD), encompassing Crohn's disease (CD) and ulcerative colitis (UC), is a chronic condition characterized by inflammation of the gastrointestinal tract that affects millions globally. IBD poses a significant public health challenge, particularly in high-income countries (Byron et al., 2020). It always comes with a long-lasting condition that results in inflammation and persistent sores in the stomach. Patients with this disease have irregular flares, which disrupt their day-to-day functioning and quality of life. Nurses also provide supportive care, and the patient is assisted in managing diseases and symptoms (Mikocka-Walus, 2019). CD and UC are multifactorial diseases, and the underlying pathological process seems to be a combination of genetic predisposition and immunologic disturbances (Szabo, 2019).

Crohn's disease can affect any part of the stomach, from the mouth to the anus, while ulcerative colitis involves only the colon and rectum. The exact cause of IBD is not known. However, it is assumed that due to the immune system's response to environmental stimuli, genetically common symptoms include nausea, abdominal pain, rectal bleeding, weight loss, and fatigue. Symptoms can range from mild to severe and notably impact on the quality of life (Naude, 2023).

According to the (GBD, 2017), the prevalence of IBD in 2017 was 6.8 million cases worldwide. The incidence is significantly high in North America and Europe, with the United States alone reporting more than 3.1 million adults diagnosed with IBD, as of 2015, representing nearly 1.3% of the population (GBD, 2017). In Europe, prevalence rates range from 5 to 15 per 100,000 people (Singh et al., 2022). Additionally, emerging economies, particularly in Asia and South America, are witnessing a rise in IBD cases, likely due to urbanization, industrialization, and changing lifestyles (Singh et al., 2022). The healthcare landscape of IBD patient care has changed in the last decade. Nurses have appeared as an important contributor to symptom management and the care of patients suffering from IBD.

In the 20th century, the incidence rate of IBD increased worldwide, especially in European countries. Finland is one of the countries with the highest IBD reported cases. Recent research by Kontola et al. (2023) established that from 2000-2020 there was a continuous spike in the occurrence of IBD. The crude incidence rate increased to 48 per 100,000 person-years, and the crude prevalence increased from 376 to 972 per 100,000 persons. (Kontola et

al., 2023). This increase has posed serious health burdens on national and international levels, including elevated morbidity rates and economic stress on healthcare systems. (Wang et al., 2023).

The importance of nursing interventions has recently caught the eye in IBD patient care and symptom management. Currently, attention to this aspect has only been given by a few countries like the USA and Canada, which is insufficient (N Rohatinsky et al., 2023). Nurses help patients by implementing individualized care plans and strengthening their knowledge of symptoms. Some of these interventions include aiding patients in identifying preliminary signs of flare-ups, administering medications, observing strict diets, and giving emotional support for the physical changes and challenges of being a chronically sick patient (Baars et al., 2019).

The choice of this topic is grounded in nurses' critical role in the multidisciplinary care of IBD patients. Nurses are often the first point of contact for patients and are integral to providing continuous support, education, and symptom management. They guide patients through treatment plans, nutritional advice, and lifestyle adjustments while offering emotional and psychological support, which is essential in managing chronic sickness's burden. Therefore, this secondary qualitative research aims to explore and synthesize existing literature on the role of nursing in the support and symptom management of patients with Inflammatory Bowel Disease (IBD). By conducting a scoping review of relevant studies, this research seeks to identify effective nursing interventions, best practices, and patient-centered approaches that improve the quality of life for individuals living with IBD. This thesis will focus on the role of nursing intervention in symptom management in patients with IBD.

## 2 Background

Inflammatory bowel disease (IBD) is a chronic gastrointestinal disorder characterized by chronic inflammation in the digestive tract (Colombel et al., 2020). There are two main types of IBD: Crohn's disease (CD) and ulcerative colitis (UC). Both are caused by an abnormal immune response in the gastrointestinal tract in which the immune cells mistakenly attack the healthy cells lining the intestines. IBD causes various types of inflammation depending on the condition. Crohn's disease can cause inflammation in any part of the digestive tract from the mouth to the anus, often affecting the entire intestinal wall. Ulcerative colitis primarily involves the colon, especially the colon and rectum (Cross et al., 2019).

CD and UC are similar in that both cause chronic inflammation in the stomach, but they differ in where they occur and how they affect affected areas (Gao et al., 2021). Crohn's disease is defined by intermittent inflammation, which extends deep into the layers of the affected interstitial spaces. It is considered ambiguous because it can occur in any part of the digestive tract, from the mouth to the rectum (Hibi et al., 2020). Usual areas include the small intestine and colon. Because of the transmural nature of Crohn's disease, it can cause symptoms such as abdominal pain, nausea, weight loss, fatigue, and growth issues when the entire intestinal wall is damaged. Ulcers and inflammation with Crohn's disease can also contribute to complications such as strictures, obstructions, or fistula formation (Kavitt et al., 2019). Ulcerative colitis, on the other hand, involves only the colon and rectal mucosa, and inflammation happens in the rectum. Still chronic, the ulcers and associated changes are embedded in this intestinal mucous membrane rather than extending through the entire thickness of the intestinal wall (Kumar et al., 2022). Characteristic symptoms include abdominal cramps, bleeding, and emergency piping. Unlike Crohn's disease, ulcerative colitis does not involve areas such as the small intestine or other organs outside the large intestine (Perler et al., 2019). However, if left untreated, it can progress and eventually affect the entire spine from the pelvis to the pelvis.

The first documented cases of inflammatory bowel disease can be traced back to the medical literature in the 1850s. However, it is not clearly defined or classified as likely to exist earlier. However, it was not until the early 20th century that physicians noticed a marked increase in developed Western countries (Roda et al., 2020). Research shows that the diagnosis and incidence of IBD have increased dramatically worldwide since the 1900s, with the highest rates occurring in northern regions such as developed North America, Europe,

and East Asia. The Nordic countries record some of the highest prevalence worldwide, with Finland and others. Scandinavian countries reporting between 120 and 220 cases of IBD per 100,000 people, according to nationwide epidemiological studies (Sulz, et al., 2020). While the root causes are not fully understood, experts suspect that increasing technology, changes in hygiene practices, and changes in lifestyle and dietary habits have contributed to the long-term rise in IBD middle income in more developed regions of the world (Torres et al., 2020).

Europe and North America have more populations affected by IBD than other regions. The number of people affected by the disease is estimated to be between 1– 1.5 million in the USA, and there are 2.2 million people in Europe. The prevalence of colitis (UC) ranges from 0.6 To 24.3 people per community in Europe and North America, whereas this rate is lower in Asia. About three percent of the population of Europe and North America are affected by the disorder and 0.3% of the population of Asia. (Stein & Shaker, 2015, p. 2).

Many cases have been reported in Europe in the last few years. According to the study, the incident rate in Europe is 505 out of 100,000 people for CD and 322 per 100,000 people for UC. The incidence and prevalence of these diseases are much lower in Asia, but the trend is on the rise. The peak age of the disease is between 20 and 30 years, with the second peak at 60 to 70 years. (Stein & Shaker, 2015, p. 3).

Inflammatory bowel disease often has two main causes, including genetics and the environment where the patient lives. Environmental factors mostly attack the immune system, and the patient experiences different symptoms. Patients suffering from UC and CD have almost the same symptoms: chronic pain and inflammation in the gastrointestinal tract (Gajendran M et al., 2018).

The gut microbiome's breakdown of nutrients protects against potential pathogens and immune system development. It is now well established that the gut microbiome relates to the development and course of IBD. Changes in the gut microbiome and sponginess of the intestinal barrier can ireregulate the immune system. Genes and surroundings can be the reasons for swearing alteration and damage to the intestines (Kang et al. 2023, pp. 2-3).

## **2.1 Crohn's Disease**

Crohn's disease is an inflammatory bowel disease that creates chronic gastrointestinal tract inflammation (Roda et al., 2020). It is characterized by deep-layer inflammation that can affect any part of the digestive tract from mouth to anus (Torres et al., 2020). Abdominal

pain, diarrhea, weight loss, and fatigue are considered common symptoms of CD (Sulz et al., 2020). The CD is connected to fibrostenotic complications that make the intestinal wall thick and strictures that cause bowel obstructions (Li et al., 2019). The condition follows a chronic relapsing course with irregular periods of remission and flare-ups (Adamina et al., 2020). Medical management of symptoms during remission and flare-ups using medications that suppress the immune system, such as corticosteroids, immunomodulators, and biologics, is the treatment for CD (Torres et al., 2020). Patients who do not respond adequately to medical therapy need surgical intervention for bowel obstruction (Adamina et al., 2020). While there is no cure for Crohn's disease, timely diagnosis and management can help control symptoms and activity of the disease.

## **2.2 Causes of Crohn's Disease**

While the exact cause of CD is unknown, it is thought to result from a complex interaction between genetics, the immune system, and environmental factors (Roda et al., 2020). Genetically, genome-wide association studies have found that more than 200 susceptibility genes relate to an increased risk of developing the disease (Roda et al., 2020). Environmental stimuli such as smoking have also been shown to influence the onset and severity of the disease (Torres et al., 2020). It is believed that genetically predisposed individuals' immune systems can destabilize easily due to environmental factors, leading to chronic inflammation (Roda et al., 2020). It appears gut microbiota dysbiosis also plays a key role, as microbial degradation and composition are associated with Crohn's disease pathology (Sulz et al., 2020).

## **2.3 Symptoms of Crohn's Disease**

Some of the most common symptoms of Crohn's disease include diarrhea that may be persistent or recurrent, abdominal pain, and fever. Abdominal pain is often acute, piercing, and centered on the umbilicus, especially in the lower right quadrant of the abdomen. In addition, patients with Crohn's disease also noticed that pain increases after meals, which could be a sign of bowel obstruction or an inflammatory mass. Patients may have low-grade or high-grade fever and may even include night sweats on CD. Besides the gastrointestinal symptoms, the patients may also notice eye discomfort, conjunctivitis and keratitis, arthralgias, dermatologic findings, mouth ulcers, anorexia, weight loss, and discomfort due to nausea, vomiting, and diarrhea (Zonderman & Vender, 2000, pp. 245-257). Weight loss is a major issue, with more than 50% of patients reporting unintentional weight loss of ten

or more pounds due to nutrient absorption and appetite suppression (Kumar et al., 2022). Fatigue also affected about 75% of patients due to anemia, pain, fever, and malnutrition (Gao et al., 2021). In addition, 40-60% of patients with Crohn's disease have symptoms of anxiety and depression (Barberio et al., 2021), which can exacerbate physical illness and reduce the quality of life.

## **2.4 Diagnosis and Treatment**

Crohn's disease is diagnosed using colonoscopy, biopsy, and imaging studies, such as those on the barium enema. This differs from histopathological examination, which usually explores transmural inflammation features typical of Crohn's disease. Further, NOD2/CARD15 gene mutation may be analyzed by genetic testing; however, this is not as common in some cases. By doing radiologic imaging, skipped lesions and stenosis, some other symptoms can be identified, which helps in the identification of Crohn's with other inflammatory bowel diseases (Wang et al., 2007, pp. 121-127).

On the other hand, CD treatment also aims to provide and maintain symptom control (Torres et al., 2020). By making lifestyle changes, mild to moderate cases can be managed, and pharmacotherapy with amino-salicylates, corticosteroids, thiopurines, or biologics targeting specific inflammatory pathways (Sulz et al., 2020). These biologics, such as anti-TNF antibodies, significantly improved patient outcomes (Torres et al., 2020). Bowel obstruction may require surgery for those with structuring or penetrating disease (Adamina et al., 2020). After surgery, patients often continue medication to reduce recurrence (Torres et al., 2020). Although there is no cure, early diagnosis, and individualized treatment can effectively control disease activity in many people with Crohn's disease.

## **2.5 Ulcerative Colitis (UC)**

Ulcerative colitis (UC) is an inflammatory bowel disease characterized by chronic inflammation and ulcers of the mucous layer in the colon, including the rectum (Kobayashi et al., 2020). The patient's immune system starts targeting its own cells, causing bleeding and inflammation in the colon's inner lining. Over time, the disease worsens, and frequent flare-ups worsen the patient's condition.

Moreover, the severity of these flares can differ from time to time and can occur in weeks, months, or even years. Sometimes, it may cause hospitalization. It varies from an acute attack simultaneously with no severe symptoms. Left-side colitis and extensive colitis are

subtypes of UC that the pattern of symptoms, frequency, and intensity can differentiate. According to Stein & Shaker (2015), left-side colitis often occurs in most patients (Stein & Shaker, 2015)

## **2.6 Causes of Ulcerative Disease**

The root cause of UC is still unknown, but the immune system gives an abnormal response to environmental stimuli, and genetic makeup is responsible for this disease. (Kobayashi, et al., 2020). According to Porter, Kalla, & Ho (2020), UC is the result of changes in genes, and some factors from the surroundings can also be the reason to provoke the disease. Additionally, Cleveland, Torres, and Rubin (2022) also contribute by confirming that genetic variations can be the reason for abnormal gut responses. (Porter, Kalla, & Ho, 2020). One more study emphasizes the external factors that make the disease worse with the changes and response in the immune system. These factors can be smoking, excessive use of drugs, and unhealthy lifestyles, which can lead to changes in the responsive mechanism of the gut genes. (Kobayashi, et al., 2020).

## **2.7 Symptoms of UC**

UC Symptoms can vary from time and during the disease. The frequency of bowel movements is one of the main symptoms of UC. Stool with blood is another sign of this disease. Additionally, abdominal pain, diarrhea, and cramping in the lower belly area are also observed as the most common symptoms. Body temperature and heart rate can fluctuate during the symptoms and acute attacks. Lab chemical tests can show low hemoglobin and a high erythrocyte sedimentation rate, which are necessary to monitor the symptoms. (Bonaz, BL, 2001).

Perler et al. (2019) stated that fever with blood in stool can be seen frequently in UC patients paired with mucus. These are the most common symptoms a patient has regarding the severity of the disease, and they also show the type of IBD. (Perler, et al., 2019). Overall, IBD disease is connected with gastrointestinal problems, but this particular type of IBD has 75% of the patient ratio who have more symptoms regarding gastrointestinal issues. In UC patients, the gastrointestinal tract and reflux can also be affected by different conditions of the disease in patients. (Hibi, et al., 2020). Some patients observed bleeding in the rectum, no hunger or feeling of appetite, and always felt tired. Pain and fatigue are commonly observed as symptoms in UC patients. (Dulai, et al., 2020). Symptoms vary in frequency of

flare-ups, with no complaints during periods of remission and severity of pain. This undiagnosed disease can dramatically affect the quality of life (Kavitt et al., 2019).

## **2.8 Diagnoses and Treatments**

Laboratory tests can determine the prevalence of the disease. Using colonoscopy as a diagnostic tool, a specialist can examine the condition of the colon and rectum. He can find the level of inflammation, ulcers, and hemorrhage. Colonoscopy biopsies help to identify the specific inflammation pattern in the samples. CRP and Fecal calprotectin are alternatives to check the exact disease stage. Different body scans, including CT scans, can exclude existing UC-related diseases (Bertani et al., 2020).

According to Porter, Kalla, & Ho (2020), Treatment aims to relieve the patient and manage symptoms (Porter et al. 2020). 5-aminosalicylates and corticosteroids can be used to cure Mild to moderate diseases along with immunomodulators or biologics to target specific immune pathways (Kobayashi, et al., 2020). Some medicines can be used to determine disease stages first. For the initial stage, Mesalamine is considered the most effective treatment for ulcerative colitis. In the next stage, corticosteroids are the second treatment for those who do not respond to mesalamine. Anti-TNF medication is considered more suitable for treating patients in the severity and last stage of the disease. It is also suggested by (Bertani et al. (2020) that Colectomy should be adopted as it makes side effects less harmful for the patients (Bertani et al., 2020).

In case of severe hypothermia, some patients may need to visit the hospital for health care services for intravenous corticosteroids or supportive care (Dulai et al., 2020). Some patients may require a colectomy to handle the situation, and antibiotics will be taken by patients who are not getting any relief from any other medicine. Nonpharmacological interventions such as nutritional therapy and lifestyle modifications can also help to control the symptoms (Cleveland et al., 2022). Early detection, diet, lifestyle modification, and an individualized care plan can make the treatment effective, and symptoms of the disease can be managed timely (Kobayashi et al., 2020).

## **2.9 Psychological Impact and Existing Nursing Interventions**

Psychosocial challenges faced by IBD patients are considerable aspects of symptom management and improving quality of life. Research based on the said topic is very little in the literature. In recent years, only 2% of data were found on the psychological and

emotional well-being of patients with IBD. Anxiety and depression are the leading indicators that tell health professionals about the mental health of a patient. According to research published by a group of researchers in 2017, 21% of cases reported clinical anxiety disorder, and 35% of patients with IBD had anxiety symptoms. Additionally, 15% had depression, and 22% exhibited depressive symptoms (Taft et al., 2017). Many therapies have been introduced to address this issue, which will be discussed in the findings.

## **2.10 Nursing Interventions and IBD**

Nurses have played a vital role in disease management and care perspectives. Nurses use emotional and physical support as their nursing intervention to minimize the effects of the disease. Educating patients about the disease is another intervention that involves learning how to manage medicine's symptoms and side effects by changing their healthy lifestyle. Nurses can provide diet, exercise, self-care activities, and stress management guidelines. Healthcare professionals may observe the patient's condition regarding daily activities, disease symptoms management, and willingness to live a healthy life. As Matsuoka stated, multiple nursing interventions are helpful to control the symptoms of inflammatory bowel disease. These strategies can enhance the coping mechanism in patients and help them understand the different stages of the disease and how to manage it (Matsuoka et al., 2018).

IBD patients suffer a lot psychologically, which is considered the most neglected part of the disease. And treatment also. Psychosocial support is a critical nursing intervention for IBD patients. Patients go through deep phases of anxiety and depression as they feel social isolation while going to public gatherings. They are always fearful of unexpected flare-ups and looking for toilets in public as a shameful act. According to (Sattoe, 2020), nurses can play their roles to identify the social distress in patients, and they can arrange some psychological help for them by referring them to clinical psychologists. With effective communication and continued support, the caregivers mitigate some of the psychological impacts of IBD by improving the patient's quality of life (Yan et al., 2020).

## **2.11 Specialized IBD Nurses**

Consequently, caregivers have a significant role in the clinical and emotional management of IBD patients, making them independent to better cope with their chronic illness (Wickman, 2019). IBD nurse is a specific caregiver who focuses on treating patients with Crohn's disease and ulcerative colitis. These nurses are a significant part of the healthcare

teams and act as a bridge between patients and doctors during treatment. Taking care of fistulas and ostomies and giving out biological therapies are their primary job descriptions. Furthermore, they offer psychological and social support to the patients by educating them about the disease, early diagnoses, symptom management, providing dietary guidelines, sexuality, and mental health (Rosso et al., 2021).

## **2.12 Person-Centered Care and IBD**

Person-centered care has become essential in nursing, especially when managing chronic diseases such as Inflammatory Bowel Disease (Fiorino et al., 2020). Patient-centered care focuses on the patient and his or her needs, preferences, and values by providing the proper care to the patient. As stated (GBD, 2017), Person-centered nursing has played a significant role in the management of IBD since the disease is complex and has a variable course that may impact the patient in different ways. Developing a good relationship with the patient, especially on matters of trust, empathy, and communication, enables nurses to handle IBD patients efficiently using the person-centered approach. Plevris (2022) indicates that effective communication can be used to understand the patient's perception of their disease and personal life experiences. These areas include what they fear, how lifestyle changes may affect daily activities, and what the patient expects from the treatment. Involving patients in their disease management decisions is very important. This is a crucial element linked with providing person-centered care in IBD. Kennedy (2020) pointed out that when patients are involved in decision-making about their condition, they are more likely to adhere to the recommended treatment plan and have higher satisfaction with the services provided.

Person-centered care also involves the social and psychological aspects of IBD, such as feelings of shame and detachment from society. This is where nurses play a crucial role in identifying such issues and sharing health, psychological, and social information. According to Nowlin (2021), for patients with chronic diseases, it is imperative to identify aspects of care beyond symptom management, especially in terms of the patient's mental health. In this way, person-centered care promotes flexibility, improves quality of life, and reduces the psychological burden of managing a chronic illness like IBD, with the patient seen as a person with a complete life.

### **3 Aim of the study**

This study aims to identify nurses' roles in managing symptoms in patients with inflammatory bowel disease. Identifying these interventions will focus on nursing practices and improve symptom management and overall quality of life. Moreover, it will discuss how patient education helps in better-managing symptoms and leads to optimal patient outcomes. Additionally, what existing nursing interventions has been using by health care professionals to cope up with emotional and psychological wellbeing.

#### **3.1 Research Questions**

The research questions are:

1. What is the role of nurses in managing inflammatory Bowel disease?
2. What are the nursing interventions that manage psychological impact in IBD patients?

## **4 Theoretical Framework**

Nursing theories and frameworks are fundamental concepts in advancing science and studies. They assist in organizing data collection, which aids researchers in making appropriate decisions. These frameworks allow disparate and isolated information to be built, studied, and processed. Furthermore, frameworks offer some guidance, thus giving impetus to enhanced research and accumulation of knowledge. This suggests that it becomes easy for authors to understand when theoretical models and theories are captured compactly. A theoretical framework is not just a pool of ideas and models but also helps a researcher understand reality in a particular situation. In research, the formulation of theories and the generation of frameworks of study are the ways that offer professional knowledge on how to gather all the evidence needed for the studies (Polit & Beck, 2012, pp. 131-132).

### **4.1 McCormack and McCance's Person-Centered Care Approach**

Person-centered care emphasizes the individuality of each patient, recognizing their unique experience of illness and promoting a therapeutic relationship between the patient and healthcare provider (Huh & Shin, 2021). In IBD management, the PCC approach is particularly relevant because the disease manifests differently in each patient, with varying severity, symptoms, and psychosocial impacts (Sudhakar et al., 2023). The changing nature of IBD, with its unpredictable flare-ups and remissions, requires personalized care plans adapted to each patient's specific needs, lifestyle, and treatment preferences (Huh & Shin, 2021). By adopting PCC, nurses can provide more holistic care, addressing the physical symptoms and the emotional, psychological, and social aspects of living with a chronic disease (Bhattacharyya et al., 2021).

This approach aligns with the core elements of McCormack and McCance's (2017) Person-Centered Nursing Framework, which provides a structured model for delivering person-centered care in nursing. The framework includes four essential components:

1. Prerequisites: Nurses' personal qualities include having the appropriate skills, knowledge, and attitudes to provide person-centered care. For IBD patients, this includes specialized knowledge of the disease, medications, and psychosocial impacts (Rohatinsky et al., 2023). Dewar and Cook (2014) noted that these are the fundamental core values that define patient-

centered care. Finally, to prevent the interference of belief on the side of the nurses, the nurses need to be conscious and believe in appropriate ways of handling the patients.

2. The Care Environment: It is necessary to establish a caring atmosphere to encourage patients to make their own decisions and discuss their treatment options (Song & Wu, 2022). A study by Dewar and Cook in 2014 found that fostering a work culture that encourages teamwork and collaborative decision-making is crucial for implementing person-centered care within an organization, especially when addressing illnesses requiring sustained patient-focused treatment and attention.

3. Person-Centered Processes: To understand patients' personal needs, preferences, and emotional state, the care process should be cooperative and involve regular dialogue with the patient. Regular check-ups on symptom management, medication adherence, and emotional support are included for a patient with IBD (Schoefs et al., 2022). Santana et al. (2018) established that the patients' decision-making regarding their treatments improves their satisfaction and adherence. Therefore, such engagement is more beneficial in conditions like long-standing or chronic IBD and is likely to require the patient's contribution towards their management.

4. Outcomes: Providing care centered around the individual leads to results, like enhanced happiness and compliance with treatment plans and an overall better quality of life for them. Bowel disease (IBD) encompasses effective symptom control, reduced hospital stays, and improved emotional and social well-being. (Yan et al., 2020). Paparella (2016) notes that person-centered care improves the patient's emotional and psychological well-being, which is crucial for patients with long-term diseases. In conclusion, patients' perception of being respected, involved, or supported results in upbeat delivery of care outcomes.



Figure 1: Conceptual framework for the theory of Comfort by American Association of Colleges of Nursing (AACN) 2024.

## 4.2 Application to IBD Nursing Care

For patients with IBD, PCC promotes shared decision-making and self-management. Nursing interventions, guided by the PCC approach, may include patient education about symptom recognition, dietary management, stress reduction techniques, and medication adherence (Sinopoulou, 2021). The unpredictable course of IBD often leaves patients feeling uncertain and anxious about their health, so the continuous support provided by nurses under the PCC framework helps build a sense of control and empowerment in patients (Byron et al., 2020).

Moreover, the biopsychosocial model complements the PCC approach by integrating biological, psychological, and social factors into patient care (Sudhakar et al., 2023). IBD is not just a physical condition; it often leads to depression, anxiety, and social isolation. Nurses address these interconnected aspects of a patient's well-being through a biopsychosocial lens, facilitating a more comprehensive treatment plan beyond managing physical symptoms (Santos et al., 2020).

## 5 Methodology

The scoping review has been used to identify nurses' role in managing IBD among patients. Scientific studies are collected, organized, and presented along with the findings and conclusion of the study. Moreover, systematic reviews help to reveal the evidential gaps in the field and the subsequent research deficiencies that need to be addressed (Sideway et al., 2019). This section will briefly introduce the concept of qualitative research and a general overview of the scoping review process. The study clearly understands the research when describing the data collection methods and discussing each article. Thus, the given approach allows the author to answer the research questions.

### 5.1 Scoping review

A scoping review examines and summarizes evidence concerning a topic by incorporating research findings. To create a thorough understanding of all existing evidence on the subject matter, this methodology, together with non-experimental proof sources, systematically sorts and categorizes applicable literature in line with pre-established criteria to meet specific goals and research inquiries while delving into basic ideas, theories, and discrepancies in the information (Peters et al., 2021).

*“Scoping reviews systematically identify and chart relevant literature that meets predetermined inclusion criteria available on a given topic to address specified objective(s) and review question(s) in relation to key concepts, theories, data, and evidence gaps”* (Peters et al., 2021).

Exploring a range of literature on a topic through a scoping review enables researchers to effectively reveal necessary ideas and gaps in knowledge. It helps establish emerging research areas or subjects with different studies and evidence types. Scoping reviews help researchers deeply understand a field before analyzing more targeted systematic reviews (Daudt et al., 2013).

A scoping review includes identifying the research question, examining the literature to select studies based on specific criteria, and organizing and summarizing the results. This method gives us a deep insight into the literature where there is no need to concentrate on the literature review, as Peters et al. (2015) noted. The outcomes of a scoping review

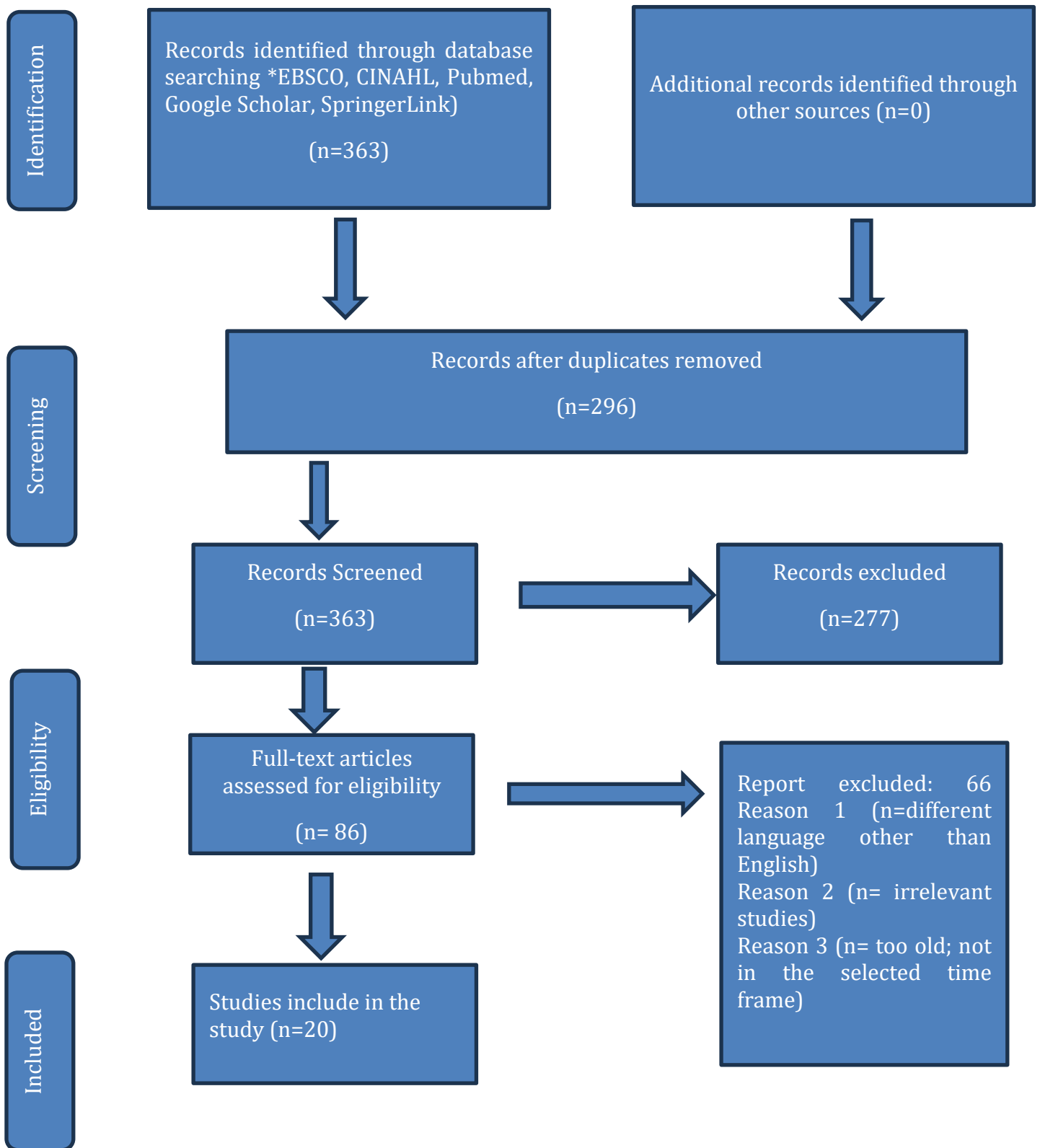
continuously explore areas where knowledge is lacking and guide research paths (Pham et al., 2014).

Scoping reviews are presented following the PRISMA. Scoping Review (PRISMA. ScRs) guidelines aim to maintain precise reporting methods for researchers and readers (Tricco et al., 2018). These guidelines draw a structure for presenting scoping reviews. To conduct a scoping review of research studies (Suchare & Macaluso, 2019) suggested six essential steps should be followed to identify and incorporate findings. Step 1: Make a research question that contains aspects of the study. Step 2: Search for studies by exploring literature sources that are relevant to your research topic, including grey literature. Step 3: Apply inclusion and exclusion criteria to select studies based on their relevance to your research. Step 4 Obtain information from the collected literature to make a data chart. Step 5: Make a report of the findings from collated data. Step 6: Consult with stakeholders to gain perspectives and validate the findings of the scoping review (Sucharew & Macalunos,2019).

## **5.2 Data Collection**

Primary research papers have been selected for analysis by using a scoping review. The study search was done by using some specific keywords and terms like ‘Nursing interventions’, ‘Nurse roles’, ‘IBD nurse’, ‘existing interventions’, ‘IBD and Inflammatory bowel disease’, ‘uncreative colitis’, ‘stoma bag’, ‘IBD and quality of life’, ‘patient education and IBD’ and many other related key terms. Many articles, books, and journals were found by searching different search engines and databases like PubMed, EBSCOhost, Medline, Google Scholar, Unpaywall, ScienceDirect, and SpringerLink. Moreover, OR and topic-related words were used as a search strategy. A PRISMA-ScR flow chart has been added to describe the details of the collected data (Polit & Beck,2009). After reading the data Lastly, 20 articles were finalized after having many other options, including books, websites, and journals. However, only articles were used to write the results and make the research more effective. Inclusion and exclusion criteria have been used to draw the most authentic information about the topic to write in the findings.

Figure 2. PRISMA 2009 Flow Diagram



### 5.3 Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria will be considered during this research,

Criteria	Inclusion Criteria	Exclusion Criteria
Language	Research only written in the English language	Research written in another language aside from the English Language
Study selection	Studies evaluate nursing interventions such as education, counseling, symptom management, and support.	The remaining studies are excluded.
Year of publication	Publications from the year 2014 to the present will be considered.	All other studies before 2014 are excluded.
Thematic Accordance	Free access, full text available, studies with IBD.	All other studies apart from IBD were excluded.
Design of the study	Qualitative and Quantitative Studies, and the final version is a scoping review.	Blogs

Table 1: Inclusion and Exclusion Criteria

## 6 Results

In this chapter, we have analyzed our 20 selected articles, as shown in the appendix. This chapter answers our two research questions. By doing a critical analysis, themes and sub-themes were created, as shown in the following table. According to the study results, four themes were created and divided into sub-themes.

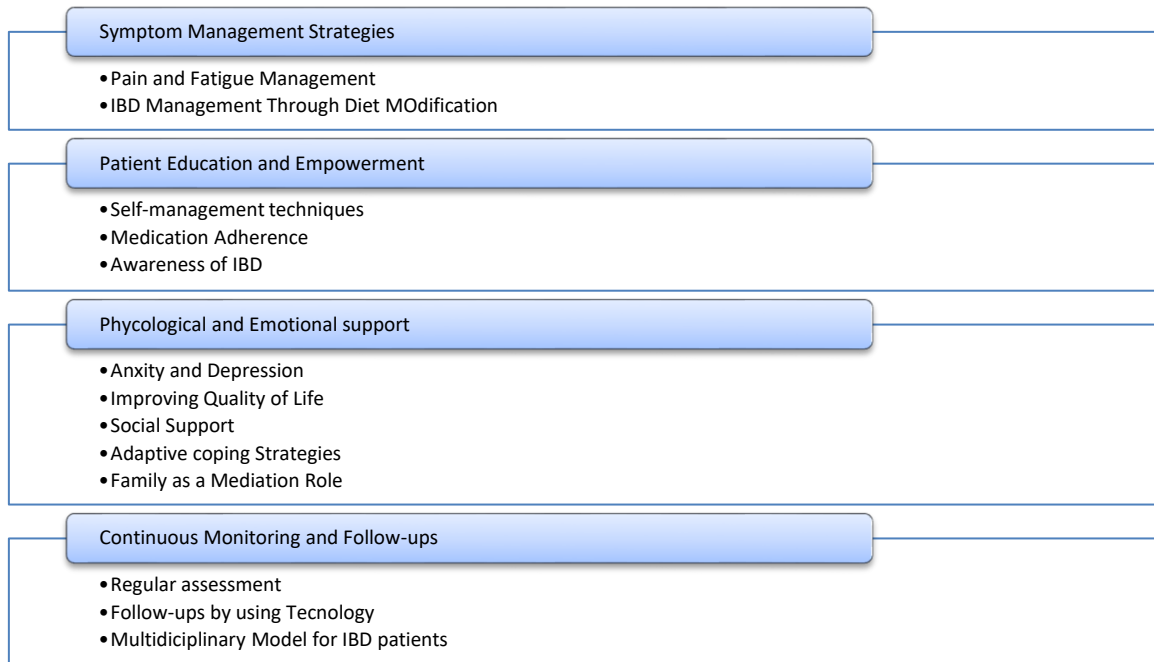


Figure 3: Theme and sub-theme

### 6.1 Symptom Management Strategies

IBD patients face a wide range of challenges, whether they are diagnosed early or at a later stage of the disease. Symptom management is a broader view of one side of the disease's impact on a patient's life. Psychological and emotional well-being also relate to symptom management, but pain and fatigue can be caused by medication and different stages of the disease. Studies also discuss nursing interventions, which will be discussed later in the results.

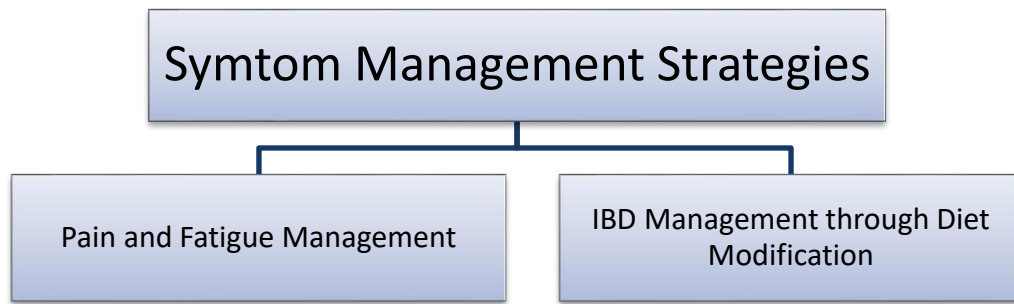


Figure 4: Theme 1: Symptom Management Strategies

### 6.1.1 Pain and fatigue management

Pain intensifies fatigue and increases urgency, which further inflames pain and fatigue. According to Dibley et al. (2021), pain fatigue and urgency have worsened impact on the health of IBD patients and formed a painful cycle of these symptoms. It is difficult for healthcare givers to treat one symptom in isolation as these are interrelated. It is also recommended by the mentioned study that nurses and physicians send a referral for screening. Treatment and individualized care plans should be combined with medical interventions and psychological support to achieve long-term healthy lifestyle goals for patients. (Dibley et al., 2021)

Another study talked about fatigue as the most oppressive symptom in IBD patients with active and non-active conditions of IBD, complaining about tiredness, lethargy, and no energy. Insomnia, lousy quality of life, and psychological distress are reported from most of the female patients. (Taft et al., 2017) Pain and fatigue limit the life of patients, and with Psychosocial impacts, patients mostly isolate themselves from social activities. There is a fear of embarrassment and incontinence while interacting with the community. Psychological and physical pain, along with fatigue, is considered the main barrier to engaging patients in social activities (Popov et al., 2021)

Nurses play a pivotal role in managing pain and fatigue in patients. Medical and non-medical interventions can be implemented favorably. As a concern with medicine-related interventions, nurses should upgrade their knowledge of pharmacology to control pain and side effects of the medicine in the patients. Nurses should educate the patient on how this medicine can benefit them, and the intake of different doses should be guided. Knowledge about pain scales can benefit clinical practices while making treatment decisions. (Golik et al., 2021)

According to Dibley et al. (2021), eating a healthy diet, physical activity, and taking care of emotional well-being can help manage physical and emotional pain. Nurses can develop online intervention programs for IBD patients to manage these symptoms. These interventions should be patient-centered and person-focused. (Dibley et al., 2021)

Hypnotherapy is an old but now-growing technique to manage the pain and fatigue in the patients. It is also used for gut health and other diseases, such as pain like cancer. Therapy is based on five to seven weeks, and results show that patients who had taken twelve sessions could manage the symptoms for five years. Ballou and Keefer (2017) mentioned in the study that results for IBD patients are still unclear, and further study is also needed to make it more effective for the patients. (Ballou & Keefer, 2017)

The nurse can arrange planning sessions with patients to develop and identify coping strategies for pain and fatigue management, such as exercise, good sleep habits, short naps during working hours, good fluid intake, and a healthy diet. The study also suggested cognitive behavior therapy, which can be used for improvement in pain and restlessness. In this regard, the role of advanced IBD nurses is vital and can be more efficient with early diagnosis and making individualized care plans. These nurses can take online follow-ups, which can make the patient's hustle less, and they will be calmer and more relaxed. It will cause less psychological and physical pain (O'Connor et al., 2013)

### **6.1.2 IBD Management through Diet Modification**

Health and a suitable diet are crucial to care plans for IBD patients, but no one can say that one diet can benefit all. Patients are concerned about the effects of diet and IBD symptoms, but the epidemiology of IBD does not strongly support dietary aids as a symptom management technique or tool. However, a dietitian specializing in IBD can work in a multi-disciplinary team to make individual diet plans according to the patient's requirements and level of disease. (O'Connor et al., 2013)

The role of food and liquid intake is an ongoing topic of research. It is also mentioned in the above research that not one specific diet can be fit for all. However, according to a study by Fawson et al., healthcare givers should be guided by maintaining a dietary diary to record food intake and symptom changes. Many online apps are also available to track food intake and outcomes. (Fawson et al., 2022)

Abdominal pain is also associated with food intake. Some patients shared their experiences after taking certain foods; they were having severe cramps and pain in the abdomen. Most

of the patients complain that they came to know with experience what kind of food suits them and when they should take specific kind of food.

*“Usually, when I drink milk by myself, I have to have diarrhea after drinking it, then I know I am intolerant to this milk or what” (Ting-Ting et al., 2023, p. 5)*

*“I experienced, like, that more lubricating intestinal stuff, such as melon, melon, banana, eat will diarrhea.” (Ting-Ting et al., 2023, at p. 5)*

*“I keep a daily diet diary and slowly try new foods to see if I can tolerate them. I prefer to eat a variety of foods from the list of foods I want.” (Ting-Ting et al., 2023, p. 5)*

Additionally, the writer suggested avoiding food that triggers the disease. Nurses should also involve dietitians in healthy meals while engaging patients with their experiences. (Ting-Ting et al., 2023)

Malnutrition is another primary concern in patients with IBD. Many nutrients are lost with stool, the body needs more energy to cope with disease, and medicine effects also cause malnutrition. It can lead patients to low sexual desire or maturation, poor mental health, and protein deficiency. Nurses should refer such patients to dietitians to add such food to meal plans to cope with deficiencies in daily food intake, and nurses should recommend good supplements that can be readily available over the counter. Liquid diet therapy is also recommended as it is cheap and safer for IBD patients. A nurse’s guidelines for Polish nurses suggest that nurses should guide patients about dieting with more fiber for a healthy gut. (Golik et al., 2014)

Patients, particularly the nurses and dietitians, must educate the patients on the process. Due to their uniqueness, the nurses can give specific diets based on patients' choices, health needs, and symptoms. Dibley et al. (2020) establish that there is a need to design intervention solutions for approaching fatigue, pain, and urgency issues regularly reported by IBD patient populations. Therefore, isolating a balanced diet plan that can enhance the health of the patients rather than causing problems in the gastrointestinal system shall enhance the patient's health status. (Dibley et al. 2020)

Moreover, a study suggested multidisciplinary models for IBD patients that can be fruitful in promoting patient engagement. This MM model also suggested referrals to counselors to discuss mental health well-being and managing quality of life living with IBD. (Popov et al., 2021)

## 6.2 Patient education and empowerment

Patient Education, Empowerment, and self-management are vital elements often missing in managing Inflammatory Bowel Disease (IBD). Knowledge of the disease, its management, and patient self-care practices empower patients to cope with their disease. This theme captures one primary emphasis on knowledge about IBD, self-management, and medication compliance and shows how these are interlinked in improving IBD profiles.

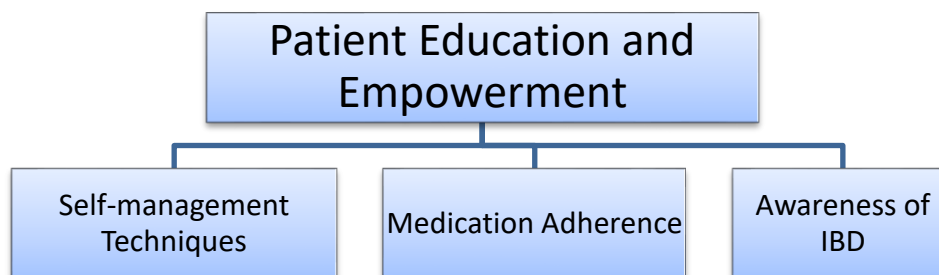


Figure 5: Theme 2: Patient Education and Empowerment

### 6.2.1 Awareness of IBD

To empower patients, it is crucial to understand and be aware of IBD in order to manage their situation. Healthcare professionals, especially nurses, provide adequate education so that the patient can enhance their knowledge about their disease, its symptoms, and available treatment options. According to the N-Ecco consensus statement, nurses play a vital role in educating patients. Emphasizing that comprehensive knowledge helps to reduce patients' anxiety and increase their ability to make reasonable decisions regarding their health (O'Connor et al., 2013)

According to many studies, awareness is essential; when patients know about their disease, they feel more in control, less fearful, and understand the situation better. A qualitative study by Mirza et al. (2022) found that patients who clearly know their disease are self-dependent

in managing their symptoms better. As a result, their quality of life improves and minimizes their overall stress (Mirza et al., 2022). The results indicate that higher awareness encourages patients to take control of their caring health journey by active participation.

Research also shows the importance of integrating digital health technologies in promoting patients' awareness of IBD. Telemedicine and mobile health apps are now used as an efficient method to improve patients' comprehension of their condition, enabling more communication with healthcare professionals and prompt access to information. A study done by Quinn et al. noted that these digital interventions significantly increase patient knowledge and awareness, which is very important for managing their disease effectively (Quinn et al., 2019). Healthcare providers create a bridge by supporting patients in their self-management efforts with the help of technology. Information about IBD become easy nowadays via internet searches and helps people to understand better how IBD is impacting their daily lives. Despite this, some also expressed that not all the information on the internet is correct. Some of the content can lead to fear and alarm, which can increase anxiety (Karadag P., Morris B. & Woolfall K., 2020).

One patient reported, “Katie, 32: I only did one Google search, *and then it started to scare me... your mind takes over about all the things that can go wrong.*” (Karadag P., Morris B. & Woolfall K., 2020).

Patients concerned about their condition, signs, and symptoms and know how to manage their condition are more likely to participate in the care. According to a cross-sectional study by CL et al. (2016), patients make a set of misconceptions regarding the comprehensiveness of their disease and non-adherence to medical therapy. This knowledge deficit is evident in managing those symptoms and feeling helpless. Consequently, an essential next step is more effective education to address IBD patients' specific informational needs (Rosso et al., 2021).

Specialized IBD nurses have an essential responsibility to explain and help patients understand the IBD conditions and management programs. Rosso et al. (2021) specify that educational interventions nurses provide can help dispel patients' concerns and improve the knowledge of patients with IBD. Nurses act as a connecting link between the doctor and the patient. During the personal teaching interventions part of the Nursing Process, the nurse can explain the meanings of specific medical terms and procedures, enabling patients to get actively involved in their illness treatment.

### **6.2.2 Self-management Techniques**

Self-management techniques for individuals living with IBD are very important, as they help patients to get involved in care actively. Moreover, by recognizing its symptoms, patients can try to implement the right strategies to mitigate the impact of their conditions. In their study, Dibley et al. (2021) said that patients who know self-management strategies feel more comfortable and confident managing their condition. That leads to fewer hospitalizations and fewer emergency visits to the hospital.

Plevinsky J. Et al. (2016) emphasize the importance of self-management to attain the ultimate health outcomes and the importance of the methods to help patients manage their health outcomes better. In this study, he mentioned educational programs to boost health knowledge, improve lifestyle choices by changing behaviors, and learn disease-specific skills like knowing signs of disease flare-ups, understanding treatments, refilling prescriptions, or scheduling medical appointments. Moreover, other self-management skills include coping skills like relaxation techniques and encouraging patient empowerment. Since self-management involves self-control and problem-solving, thus it is crucial to build confidence and problem-solving abilities in patients. Learning those problems to handle confidently can maximize patients' self-management ability. This ability helps patients feel more in control of their disease rather than feeling that the disease is controlling. (Plevinsky J. Et al., 2016).

### **6.2.3 Medication Adherence**

Medical adherence (MA) means whether patients are taking their prescribed medication according to recommendations. Inadequate MA may result in worse health outcomes, including increased disease flare-ups, complications, and healthcare costs. Studies done by Amiesimaka et al. (2024) reported that non-adherence IBD patients have a much higher risk of relapse compared to adherent patients. This research also mentioned that up to one-third of patients with IBD may struggle with adhering to their prescribed medication schedule. However, this rate can vary depending on geographical and demographic factors (Amiesimaka et al., 2024).

The study by Rosso et al. (2021) noted that medication adherence in patients with IBD is a complex issue. According to the research, there is only 57% of IBD patients have never missed a single dose of MESALAZINE, which points to a significant problem with treatment adherence. Many factors influence MA and are not genuinely connected to the prescribed

therapy. These factors are patients' lifestyles, psychological support, and complications managing their condition during the visit. The responsibilities of IBD nurses are to emphasize promoting MA by providing patients with support and education. By doing this, nurses help patients to understand their treatment plan and encourage regular medicine use. Moreover, it is also highlighted that patients need psychological support, and this is necessary during visits to improve MA and overall care results (Rosso et al., 2021).

### 6.3 Psychological and Emotional Support

Patients dealing with IBD suffer in many ways; psychological and emotional well-being is a severe concern to manage the disease to improve their quality of life. Mental health-related issues are highly connected to the appraisal of disease symptoms in daily life.

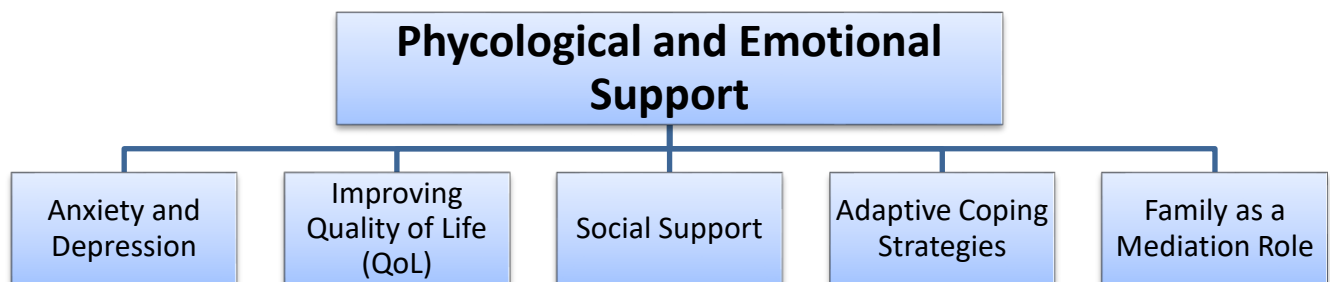


Figure 6: Theme 3: Psychological and Emotional Support

#### 6.3.1 Anxiety and Depression

Psychosocial and emotional breakdowns are commonly faced by IBD patients are considerable aspects of symptom management and improving QOL. Anxiety and depression are the clear indicators for health professionals to diagnose and cure the acute condition of the patient. Clinical depression, anxiety and distressed breakdown cases are reported to the health care system, but this aspect is always on neglected side. Many patients themselves faced the distress and report to the doctors but there is no pre-defined nursing intervention has been found in the previous studies. Some common therapies and treatments are there but to address the issue is the first step that always considered at least important side. (Taft et al., 2017).

Stress management is also complex for the patient to achieve as people live in far-flung areas from leading clinics in the city; many patients report their stress levels related to the symptoms, uncertainty of the situation, and long travels (Lauralie et al., 2020). A study was conducted in New Zealand on the living experience of the patient in 2020. Patients from rural areas were selected as a sample, and they shared their experiences on daily life management and stress. Participants explained that living with IBD is itself stressful. However, when traveling to the main cities, different factors worsen their symptoms and anxiety, like transport, cost, and preparing suitable food before leaving. (Lauralie, Geoff & Sarah Derrett 2020).

Some patients faced a swear phase of depression and denial of disease in the diagnosis process. Along with fear and anxiety, they feel sadness, stigma, shame, and a feeling of anger. (Richard et al., 2020) Psychosocial impacts and feelings controlled by IBD are the worst challenges faced by the patients, which increase stress and anxiety. Most young people feel social isolation, loneliness, and low self-esteem. They feel shame and panic while facing the social gathering around them. This feeling leads to depression and a rise in the level of anxiety, which creates fear and insecurity among them (Popov et al., 2021).

According to a patient's perspective

*“Just once before I leave this world, I would like to go to any kind of function and just sit down and not say, 'Where is the bathroom?’” (Popov et al., 2021, p. 126)*

According to Ballou & Keefer (2017), IBS and IBD have a real connection related to symptoms and health conditions, and patients face almost the same kind of psychological issues. To address the triggers of psychological interventions can be beneficial to the patients with IBD and IBS. This study strongly referred to three kinds of therapies with more evidence of patients' mental health. Hypnosis, based on mindfulness therapies and cognitive behavior therapies, is highly recommended to overcome anxiety and depression in patients with IBD.

### **6.3.1.1 Cognitive Behavior Therapy**

CBT for IBD has shown promising results in adolescents. It was found that CBT had a favorable impact on the improvement of living quality and management of symptoms, anxiety, and depression for adolescents but less for adults. Patients learn in a specific

environment with predefined instructions on coping with symptoms, daily activities, and stress management. (Ballou & Keefer, 2017)

### 6.3.1.2 Hypnotherapy

Hypnotherapy is also considered a helpful therapy for both physical and psychological symptoms, especially for overcoming negative thoughts and self-image management. Patients followed a five-to-seven-week hypnosis recorded track to focus on the psychological symptoms and outcomes. It is not used officially in hospitals, but only some studies show that it gives tremendous results for patients. It is an ancient way of treating patients with their stress and anxiety management. (Ballou & Keefer, 2017)

### 6.3.1.3 Mindfulness-based Therapy

Mindfulness-based therapies use relaxation and meditation techniques to help patients focus on the present moment without judgment. It aids in coping with emotional distress related to disease symptoms. Studies have demonstrated that MBT reduces anxiety and depression, improves psychological well-being, and enhances the quality of life in IBD patients. Although there is less research on MBT in IBD compared to IBS, it has been shown to provide lasting benefits, with some effects lasting up to six months (Ballou & Keefer, 2017)

The role of IBD nurses is vital to refer patients to psychological therapies and social support groups and clinical psychologists who can guide patients on how to overcome stress, which is interrelated to increased disease indicators. According to (Dibley et al., 2021), IBD specialist nurses are a valuable source of emotional and on-ground support for how they can manage their stress. Nurses can make individualized plans for them according to their needs so they can be listened to timely for emotional distress. (Dibley et al., 2021)

As per a patient's perspective

*“IBD Nurses are not dismissive, and they will answer your questions and make you feel at ease rather than, yes, see you in six months” (Dibley et al., 2021, p. 3338)*

Another study on the role of nurses and interventions shows that individualized psychotherapeutic interventions can improve a good relationship between therapists and patients. The respective nurses can make these unique plans with follow-up and adherence to quality medical services. These therapy sessions should focus on each patient's circumstances and school or work environment, and they should include extraordinary

correspondence between schoolteachers or management staff at workplaces and medical professionals. This written material should include caring instruction for patients with IBD and creating a healthy environment. This way, they can feel mentally relaxed and confident about their careers. (Popov et al., 2021)

### 6.3.2 Family as a Mediation Role

Patients with IBD face mostly social isolation not only at work or school but also at home. According to (Popov et al., 2021), family and friends are important factors to manage psychological and emotional wellbeing. As the study shows, pediatric patients get good treatment at clinics because of access to medicine, health professionals, and social workers, but limited resources were given to adult patients. A patient's family and community support suits the medication process. (Popov et al., 2021)

A participant in the study mentioned,

*“Having good support at home helps a lot, too—somebody who understands that not every day will be good. You are going to have some bad days. When it was just myself, before I got with my current wife, it was hard because when you have those down days, and there is nobody there to help you, you wonder if it ever is going to end, and then all it does is manifest the disease even more.” (Popov et al., 2021, p. 126) “*

Moreover, patients with low self-esteem also suffer a lot regarding symptoms of the disease and mental health. A study was conducted in China for the family function and relation with symptoms of depression. As per the results of the research, health professionals can take a glance at the mental health of an IBD patient, as a good family function provides a high level of peace of mind and a relaxed environment for the patient. Additionally, a low family function has a high level of depression symptoms in patients (Wu et al., 2022).

Family functioning plays a vital role in improving mental health in IBD patients. In Chinese culture, families are considered the most reliable source of social support due to the strong bonds formed through blood ties. By providing emotional and behavioral support and teaching family members effective problem-solving strategies, IBD patients can reduce the likelihood of developing mental health issues (Wu et al., 2022).

At the time of initial diagnosis, it should be considered to involve family and partners so they can be educated regarding the symptoms of the disease and the patient's psychological needs. (Popov et al., 2021) recommended that family-based counseling by IBD nurses should be included in treatment as an alternative method. IBD information-based written scripts

should be provided to the family so they can learn how to relax during distressing moments. IBD nurses should prepare family and patients together about flares, anxiety, and pain associated with symptoms. Health professionals can involve families along with patients to develop an individualized treatment plan, including medical and non-medical interventions (Popov et al., 2021)

IBD nurses play a vital role during diagnosis and early intervention involving families and patients. A study shows that participants were satisfied with the nurse's role, as they mentioned (Karadag et al., 2020).

*“I think she has been like an integral part of like my mindset now as well, and like my road to recovery cause I just feel like she is just sorted it all for me” (Karadag et al., 2020, p. 363)*

According to a study based on guidelines for the nurse's role in Poland, clear communication with the families of IBD patients should be developed. It will help nurses to create a suitable care plan for the patients. Communicating and involving the patient's family along with the patients in the care plan will make a clear path to manage the disease symptoms and mental health of the patients with IBD. Nurses should educate families about therapeutic procedures, possible complications, and patients' expected changes in body and mood. (Golik et al., 2014)

### **6.3.3 Adaptive Coping Strategies**

According to Dibley et al. (2021), most coping strategies were developed by the patients based on experience and outcomes of different treatments. Participants reported many practical interventions they applied to manage their stress, pain, and control of disease. Participants reported several practical strategies they adopted to self-manage their symptoms of fatigue, pain, and urgency, generating a sense of control over their situation. A participant mentioned urgency, which is linked with stress and anxiety, and how he coped with it. According to a study participant, he adopted yoga to manage his mental health and tried medication a lot to control stress (Dibley et al., 2021, p. 3338)

Simultaneously, another response was to take positive steps for the excellent management of anxiety and emotional distress. Monitoring the activity level is also a coping strategy adopted by a patient. The use of heat bottles and head pads is also another experience-based

intervention followed by the patient (Dibley et al., 2021) as a patient mentioned the effectiveness of hot pads and heat bottles that it relieved his symptoms for almost a year, along with hot showers works magically for him (Dibley et al., 2021, p. 3338) Some patients admired the role of exercise and physical activity to manage IBD symptoms and distress, one response was about the feeling good after doing exercise and all physical activities during exercise felt like an average person. (Dibley et al., 2021, p. 3338).

#### **6.3.4 Social Support**

Social isolation is another big challenge faced by patients with IBD. They want to stay at home or in their private space as they feel embarrassed while sitting with others and feel flares that can be up time. To address this concern, Fawson et al. (2022) suggested that there must be a social support group to maintain the emotional distress and self-esteem of the patients. Like-minded people who also have the same disease can also connect through these social groups where they can discuss coping strategies and their symptoms. Early diagnoses and discussion about life management can also be considered as a benefit from these groups (Fawson et al., 2022)

According to Popov et al. (2021), community-based groups help alleviate distress regarding disease, and coping strategies can be found within these groups.

Karadag et al. (2020) proposed a “proper community” concept in their research. According to the study mentioned, this community highlights how online platforms and social media can be helpful for patients with IBD. This community provides a supportive space for all to discuss their experiences with diagnoses, medical treatment, and the psychological burden caused by disease. The author proved from the research that social media is pivotal in emotionally supporting such people. They can educate and motivate each other to live a better life. (Karadag et al., 2020)

Some participants in the research who were using such communities shared their thoughts about how they found them beneficial.

*‘I just like seeing other people ... having so much confidence, and I am like, oh, I will be like that one day’ (Karadag et al., 2020, p. 364)*

*“I think it is good to see other people who are living with the same condition, and how they are managing it. It makes me feel like I am not alone and that one day I will be able to manage as they do” (Karadag et al., 2020, p. 364).*

Another study by Dibley et al. (2021) discussed the role of social media and online support groups. Participants in this study also use online platforms to get information about disease management. The primary outcome of these social support groups is managing distress and mental health. These groups provide a protective environment for patients to discuss without fear of judgment from others. These social groups and networks are considered safe spaces for IBD patients. Some participants in the study stated

*"Social networks were considered beneficial; participants learned about managing IBD and the associated symptoms of fatigue, pain, and urgency from others either in face-to-face meetings run by local support groups or via internet chat rooms and support pages"*(Dibley et al., 2021, p. 2821)

*"Nothing helps more than talking to someone else that has [IBD]"* (Dibley et al., 2021, p. 3339)

*"I come out of those meetings feeling good because you can just talk about it really openly, and also you get to hear about what other people are doing and experiencing"* (Dibley et al., 2021, p. 3339)

Golik et al. (2014) also discussed social networks and community groups. He mentioned these groups as associations, including the ‘‘Polish Association Supporting People with Inflammatory Bowel Disease’’ where the health professionals, patients, and patient's families are also part of these associations and can exchange knowledge, guidelines, and supportive material through knowledge-based text and websites. Within the association, different groups give information about diseases, encourage patients to adopt therapeutic processes and meet with health professionals and other patients. These guidelines about nurses' roles also emphasize the dynamic role of nurses who can connect with patients, families, and health caregivers. (Golik et al., 2014)

### **6.3.5 Improving Quality of Life (QoL)**

The impact of IBD on patient quality of life is a challenge in many ways. IBD not only creates physical symptoms like pain, fatigue, and diarrhea but also causes psychological distress. Patients' concerns about the origin of the disease, upcoming surgery, loss of bowel control, and body image issues impact their relationships and work (O'Connor et al., 2013).

Furthermore, the same study highlights that up to 74% of IBD patients may get fecal incontinence. However, this issue is rarely marked. This issue can severely minimize social interaction and isolate the person from the rest of the world (O'Connor et al., 2013).

According to a study by Golik M. et al. (2014), A patient's life with IBD is notably changed by the chronic characteristic of the condition and possible complications. Moreover, it is also highlighted in the study that IBD can lead to a remarkable decrease in the patient's quality of life. In addition, it points out, *"Patients feel alienated, pushed to the margins of society. They are often forced to stop working or attending school or college."* This dissatisfaction, together with the physical signs of IBD, like stomach discomfort and chronic tiredness, can lead to poor self-esteem and loneliness.

The article also states: *"Quality of life is a subjective value, and only patients can describe it properly. In the case of IBD, quality of life is significantly reduced, especially during periods of exacerbation."* (Golik M. et al., 2014)

The authors also say, *"Nurses must be able to identify patients' needs, find coping resources that are available for them, and plan care so that patients' comfort of life is maximally improved."*

Due to their close contact with the patient's nurses, nurses' roles significantly improve the quality of life for patients with IBD. Through empathy and effective communication, nurses can create a positive atmosphere that builds excellent nurse-patient relationships. A nurse's primary responsibilities include helping patients cope with their feelings of helplessness, encouraging them to participate in their health management, and helping them to better their overall well-being (Golik M. et al., 2014).

Another study by Ballaou and Keefer (2017), even though no study has proven that behavioral or self-management therapy is effective. But, the goal of this therapy is to identify negative behaviors like poor medication compliance or dietary non-adherence and to improve QoL. This treatment is based on the CBT concept but does not include the cognitive component of typical CBT, which analyzes harmful or irritating thinking patterns. The studies that have assessed Behavioral/Self-Management for IBD have revealed that this may help to improve health outcomes and QoL (Ballou & Keefer, 2017).

## 6.4 Continuous Monitoring and Follow-ups

Some measures included are as follows: IBD requires regular follow-up and monitoring after treatment. We present the conclusions about regular assessment and the utilization of technology in patient management, which are shown to enhance the quality of ongoing management. This, in turn, enables timely and optimal interventions to be delivered to patients depending on their needs.

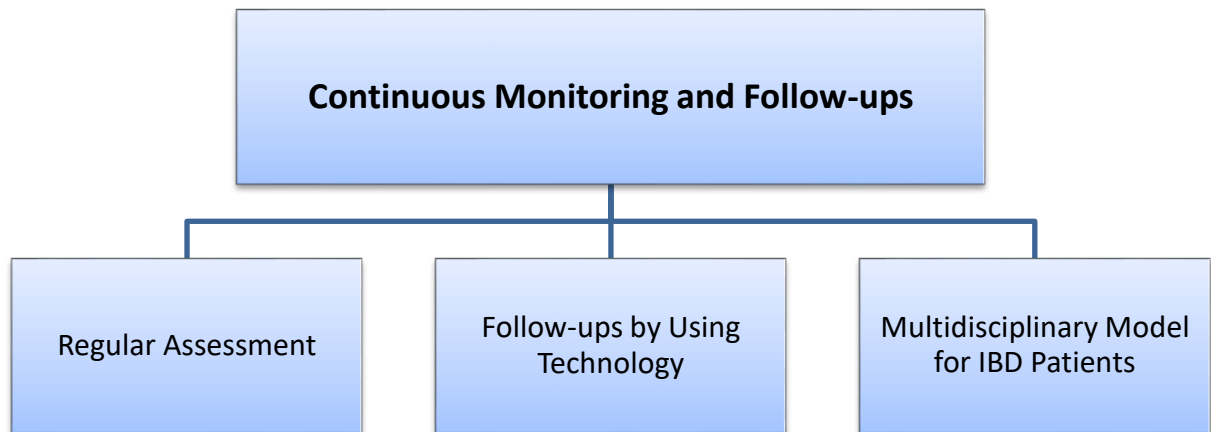


Figure 7: Theme 4: Continuous Monitoring and Follow-ups

### 6.4.1 Regular Assessment

It is essential to understand that regular monitoring of the disease activity, assessment of the treatment response, and global health of the patient with IBD are based on continuous assessments. Plevris and Lees (2022) state that systematic evaluation helps caregivers see changes in symptoms and overall health to review treatment plans. Such assessments are decisive for primary and secondary prevention to keep the patients in remission and address problems that arise that can cause complications. In addition, Gu et al. (2024) synthesized a meta-analysis showing that consistent follow-ups contribute positively to patients' health. Their results stress the importance of an approach for patient notes, with patient visits, diaries, and clinical reviews to assess the decline of the conditions and the effectiveness of the applied medications and plans.

Regular checkups are essential for IBD patients for effective management of IBD. Patients should have a regular follow-up to identify illness flares before they become acute. Because of the long queue and other unwanted issues, patients may only visit the clinic or hospital two or three times a year; for this reason, remote monitoring becomes essential. Even though

there are many monitoring tools available that are intrusive to patients, these are expensive and create an administrative burden on clinical teams. Moreover, the results of monitoring tools also need to be documented, and action should be taken according to schedule. As a result, not every patient can get the opportunity with the same intensity, which is not even appropriate. Thus, devices that enable faster response for monitoring are recognized as vital to ensure strict disease control. Point-of-care (POC) and Remote monitoring are critical components of regular assessment. Rapid POC testing for biomarkers like C-reactive protein (CRP) and fecal calprotectin (FC) can be done outside the hospital or at home. This allows patients to do the test whenever needed and minimizes frequent hospital visits. Besides cross-sectional Imaging, Ileo-colonoscopy and capsule endoscopy are used for regular health monitoring (Plevris et al., 2022).

#### **6.4.2 Follow-ups by Using Technology**

The use of technology in managing IBD has dramatically increased how patient follow-up is administered. Telemedicine, eHealth technologies, and social media facilitate continuous interaction between the patient and the service provider and thus increase patients' involvement. For example, the TELE-IBD clinical trial by Quinn et al. (2019) showed not only the tangible accessibility advantage of telemedicine but also engaged patients' activity. This approach means that real-time feedback enables changes in treatment delivery as and when the patient communicates their experience. In addition, the self-management intervention of developing programs that are accessible online for fatigue, pain, and urgency has also been identified as beneficial for patients.

Fawson et al. (2021), in their article, pointed out that these programs assist patients in being proactively involved in self-management of the symptoms and, at the same time, assist the patients in effectively communicating with the healthcare providers. Using technology to get the patients' reports opens a platform for getting feedback that would help in decisions regarding the continued treatment process. In a systematic study done by Nguyen et al. (2022) focused on monitoring IBD, it was identified that mobile and web-based applications are beneficial for the remote tracking of disease situations, accessing care, and involving patients. However, it did not justify that there is a more substantial benefit in preventing disease flare-ups or encouraging compliance than maintenance treatment. The experience of initializing digital health technologies may help decrease health-service usage and expenditures but does not promise to enhance the quality of IBD patients' lives.

The research on Telemedicine for patients with inflammatory bowel disease (TELE-IBD) examines the possibilities of technology-based care by managing IBD at a distance. Within a TELE-IBD system, the patient can report his/her symptoms, get individual responses and action plans, and receive text messages with educational content. Although the respondents regarded it as helping in self-care and communication with health providers, the approach had challenges, including repetitive evaluations and insufficient customization of materials. The research pointed out that telehealth benefits usual care, especially for patients far away from their providers or who need to be monitored regularly (Quinn C. et al., 2019).

#### **6.4.3 Multidisciplinary Model for IBD Patients**

The Multidisciplinary Model (MM) for IBD patients is a team-based approach where nurses, specialized IBD nurses, nutritionists, psychologists, surgeons, and specialized doctors in gastroenterology can team up. The goal of this MM is to provide a wide range of coping strategies based on medical and non-medical adherence to overcome challenges related to diet, stress, anxiety, and other emotions related to disease. Popov et al. (2021) described in research that by adding these strategies, MM ensures that each patient receives comprehensive care, ensuring a better life with disease management and fewer hospital visits. Popov et al. (2021) also mentioned critical points for managing diet and awareness about disease. By adding the model mentioned above, social support groups can be broader and more beneficial for patients and health workers so they can know about different patients and their management approaches (Popov et al., 2021).

## 7 Discussion

This study was conducted on the role of nurses and nursing interventions in managing IBD in patients. It has been discussed about the psychological impact of the disease and what are the existing nursing interventions to cope with it for patients with IBD. The study has multiple themes based on symptom management, both physical and psychological, including pain and stress. Along with this, the importance of knowledge-based awareness about disease has also been described scientifically. This is a scoping review; some limitations and suggestions will be discussed later.

The first theme, Symptom management strategies, and sub-themes under it describe the symptoms and their management according to health care plans. Also, it talks about the role of nurses and how healthcare professionals can make individual care plans to manage the symptoms in IBD patients. Pain and fatigue result from physical and psychological stress, and the symptoms worsen with time. According to Dibley et al. (2021), pain fatigue and urgency have worsened impact on the health of IBD patients and formed a painful cycle of these symptoms. To overcome this, treatment and individualized care plans should be combined with medical interventions and psychological support to achieve long-term healthy lifestyle goals for patients (Dibley et al., 2021).

Nurses play a pivotal role in managing pain and fatigue in patients. Medical and non-medical interventions can be implemented favorably. As a concern with medicine-related interventions, nurses should upgrade their knowledge of pharmacology to control pain and side effects of the medicine in the patients. Nurses should educate the patient on how this medicine can benefit them, and the intake of different doses should be guided. Pain scales can benefit clinical practices while making treatment decisions (Golik et al., 2021). According to Dibley et al. (2021), a healthy diet, physical activity, and emotional well-being can help manage physical and emotional pain (Dibley et al., 2021).

Along with cognitive behavior therapy, advanced nurses can add a modified diet plan to help manage the symptoms. Although in some studies, patients are not satisfied with the role of professionals in diet guidelines, many people manage their diet according to the suitability and impact of any food item after taking and observing its effects. Nurses should make individualized diet plans with the help of nutritionists (O'Connor et al., 2013). Nutritional intervention is evident since some foods may precipitate or alleviate signs, as asserted by the

patients (Yin Ting-Ting et al., 2023). Nurses must prescribe such treatments as proper diet regimes on top of the medication, relaxation techniques, etc. (Artom et al., 2017; Dibley et al., 2020).

The next theme is Patient education and empowerment; the sub-themes are self-management techniques, Medication adherence, and Awareness of IBD. The findings of this study focus on knowledge and awareness about the disease, and it is discussed that Awareness is essential in many studies considered in the thesis, as patients feel more in control and less fearful if they understand their situation better. A qualitative study done by Mirza et al. 2022 found that patients who have an explicit knowledge of their illness allowed them to manage their symptoms in a better way, thereby increasing their quality of life and minimizing their overall stress (Mirza et al., 2022).

Self-management strategies have been discussed as a sub-theme, and the study has shown their importance. Plevinsky J. Et al. (2016) emphasize the importance of self-management to attain the ultimate health outcomes. Moreover, other self-management skills include coping skills like relaxation techniques and encouraging patient empowerment. It is essential to help a patient adjust to some aspects of life through self-management support, including diet change, stress management, and identification of signs and symptoms. Teaching people how to take responsibility for their well-being enables them to manage their chronic illnesses better (Plevinsky et al., 2016). Some nursing interventions encompass educating patients on pragmatic practices for life and motivational/emotional coping mechanisms for day-to-day symptom management. (Plevinsky J. Et al., 2016). The study by Rosso et al. (2021) noted that medication adherence in patients with IBD is a complex issue. According to the research, only 57% of IBD patients have never skipped a single dose of mesalazine, indicating a significant problem with treatment adherence. Many factors influence MA and are not truly related to the prescribed therapy. The role of IBD nurses is emphasized in promoting MA by providing patients with support and education. (Rosso et al., 2021).

Psychological and emotional well-being is another prominent theme with sub-themes on anxiety and depression. It has been discussed how stress can trigger the flares and intensity of symptoms. During this study, we researchers found that psychological health is the most neglected area in health care for patients with IBD. In recent years, only 2% of data were found on the psychological and emotional well-being of patients with IBD.

According to research published by a group of researchers in 2017, there were 21% of cases reported clinical anxiety disorder, and 35% of patients with IBD had anxiety symptoms.

Additionally, 15% had depression, and 22% exhibited depressive symptoms. (Taft, Ballou, Bedell, & Lincenberg, 2017) Stress management is complicated for patients who are from far-flung areas. Some patients faced a swear phase of depression and denial of disease in the diagnosis process. Along with fear and anxiety, they feel sadness, stigma, shame, and a feeling of anger. (Richard et al., 2020)

The second question is related to existing interventions for managing psychological health. As mentioned in the results, the researcher found some existing interventions in a study. These are not medical interventions but support from family and social groups. Also, change in lifestyle, including exercise and food modification. A patient's family and community support suit the medication process. (Popov et al., 2021). Some patients admired the role of exercise and physical activity in managing IBD symptoms and distress; one response was about feeling good after doing exercise, and all physical activities during exercise felt like an average person. (Dibley et al., 2021, p. 3338).

To manage this issue, there must be a social support group to maintain the emotional distress and self-esteem of the patients. Like-minded people who also have the same disease can also connect through these social groups where they can discuss coping strategies and their symptoms. (Fawson et al., 2022) Karadag et al. (2020) proposed a “proper community” concept in their research. According to the study mentioned, this community highlights how online platforms and social media can be helpful for patients with IBD. Nurses play a vital role in improving the quality of life for patients with IBD. By empathy and effective communication, nurses can create a positive atmosphere that promotes excellent patient relationships. (Golik M. et al., 2014).

In the end, the study finds continuous follow-up and monitoring as an existing intervention that can be useful for patients' education, managing symptoms, and achieving a mentally healthy lifestyle. Plevris and Lees (2022) state that systematic evaluation helps caregivers see changes in symptoms and overall health to review treatment plans. In addition, Gu et al. (2024) synthesized a meta-analysis showing that consistent follow-ups contribute positively to patients' health (Gu et al., 2024). The use of technology in managing IBD has dramatically increased how patient follow-up will be conducted. The research pointed out that telehealth benefits usual care, especially for patients far away from their providers or who need to be monitored regularly (Quinn C. et al., 2019).

From a clinical point of view, such findings define areas with practice-based relevance. Education should be targeted at the patients requiring one-on-one teaching that considers the

patient's health literacy and cultural background. Training should put in place skills of active listening and counseling with nurses. Standardizing team conferences, documentation, and family integration also improves coordinated care. There is evidence that incorporating mHealth may advance patient-nurse interactions. Using a checklist ensures the standard way of undertaking symptom surveillance is followed. Encouraging environments conducive to open home communication creates a way forward for better adherence and reduced anxiety. The distribution of coping resources at the regional level solves the availability problem.

Individualized care for individuals is essential in handling Inflammatory Bowel Disease (IBD) as it centers on tailored treatment strategies that consider the symptoms and patients' emotional and social well-being. According to McCormack and McCance's theory on Person-Centered Care (PCS), recognizing patients as unique individuals is crucial for managing IBD, given the term and intricate characteristics of the illness. People with bowel disease (IBD) frequently face symptoms that influence their daily lives, including pain and fatigue, along with emotional challenges. By adopting a patient-focused care strategy, healthcare professionals can customize their treatment plans to cater to each patient's requirements, thus ensuring the management of both physical symptoms and emotional well-being. This personalized approach has demonstrated results in enhancing contentment treatment compliance and overall health results. (Mirza, R. M. et. al., 2022).

In our thesis, which focuses on nursing care for patients with IBD, the theory of Person-Centered care plays a vital role in improving education and empowerment goals by enabling nurses to collaborate with patients in designing care plans that consider their preferences and life experiences. Improving symptom control does not just help with patients' well-being but also encourages them to take charge of their health by following treatment plans and coping better with the challenges they face in managing their condition. Especially when they feel listened to and encouraged along the way. The connection between McCormack and McCance's theory and these objectives highlights how nurses offer care that addresses the symptoms of IBD and promotes the patient's holistic wellness.

In IBD, patient education is crucial to minimize the effect of symptoms and enable patients to understand their condition. Nurses also play a crucial role in helping the patient learn about his/her condition, ways to avoid exacerbation, and how to achieve remission. As Sinopoulou (2021) pointed out, the more patients comprehend IBD education, which includes characteristics such as chronic and unstable flares, the higher the likelihood of adequate treatment adherence by enhancing the patient's overall health.

Good patient education practice includes making patients recognize the causes of their symptoms, such as dietary indiscretion, stress, and non-compliance to medication. In the D'Amico et al. (2020) study, the nurse informs patients on how best to avoid such triggers through activities such as dietary changes and identification of symptom flare-up cues. The nurses give the patients personal counseling to ensure that they can cope with the condition and minimize the occurrence and intensity of the symptoms.

Nurses are critical in teaching the patient how emotionally and psychologically to cope with the stresses of living with the disease. As noted (Mancina 2020), due to the chronicity and unpredictability of the disease course, anxiety and depression are frequent comorbidities in IBD patients, and training in mental health resources, stress management skills, and peer support organizations can be very helpful in reducing such a burden.

Moreover, educating a patient empowers him and makes him independent in health matters. Well-educated patients are proven to be more often involved in their care, demonstrating increased confidence in symptom management (Dulai et al., 2018).

Overall, the findings of the results show that there are not many interventions for IBD patients that can be effective on a large scale. Social support and family are neglected as a role in managing the disease with patients, but many patients and families started as their initiative. The study shows that family, friends, and social platforms can be helpful both in psychological and physical health. Patient education is another key feature that can be considered an effective intervention to manage disease for patients and their families. On the other hand, we cannot ignore the importance of medication, hospital setups, and the role of nurses in healthcare setups. Specialized IBD nurses play a vital role, but this concept is very new, so not every hospital setup has IBD nurses. Most of the developed countries in Europe, the USA, and Canada focus on the appraisal of IBD staff in normal hospital setups and private clinics.

## 8 Study Limitations

During the study, researchers noticed some limitations, such as the fact that there is not much data available on nursing interventions. There are some guidelines and personal experiences for patients and their families online. Most of the feedback suggested by the patients that the doctors neglected to address their concerns about diet, although they found diet very effective for symptom management. The nurse's role is limited to hospital setup and clinics.

The constraints of a study refer to the difficulties or obstacles that researchers may face. The research process is important as it provides meaning to the reader (Ross & Zaidi Parama, 2019). The researcher aimed to utilize a review of existing literature. During the review process of data collection, the research project faced difficulty in finding several high-quality articles for this review. As we delved into our research, we had to adjust our methodology. So, we altered to a scoping review because of the evolving nature of this research topic. The researcher ensured that the chosen articles were analyzed impartially in this study despite the bias linked to the review method used.

### 8.1 Recommendations for Nursing Practices

Specifically, implement and improve the paradigm of structured education, including Health literacy interventions and relevant cultural values for patients. The essential concepts relevant to a disease, self-care, and medications shall be uniform to ensure that individuation cannot compromise the knowledge that citizens gain (Beauchamp et al., 2022).

Train nurses to empower patients through motivational coaches. More effort must be put into one's belief in dealing with specific tasks or challenges rather than one's ability to remember specifics. Involve family/caregivers in the games (Saleh et al., 2022).

Initiation of nurse-led psychosocial support services or groups. Such facets could include the best coping methods for dealing with diseases, association with other patients who must serve as mentors, counseling services, and stress management (Flaubert et al., 2021). Help patients develop individual symptom management strategies while considering preferences regarding diet, what types of activities worsen pain, and the availability of technologies for monitoring chronic conditions (Trivedi et al., 2022). If possible, approachable materials such as yoga and acupuncture should be considered trial integrative options.

Defining the nurse coordinator's role in managing care across multiple disciplines. Organize huddles to discuss specific patients, share new information, and ensure a coherent plan is used across clinical disciplines and environments (Karam et al., 2021). Engage nurses in handoffs or handoff communication during continuity of care. They will engage the participants, conduct outreach calls and telehealth follow-ups, and identify high-risk patients who require close monitoring (Lieng et al., 2019).

The present study has provided a comprehensive study about the impact of the role of IBD nurses in the management of patients, along with enhancement in patient education and awareness. Along with this, some topics will also provide relevancy to the literature. However, it is still necessary to discover prospects for appropriate involvement and hands-on supervision, by resource of which the financial load of this illness can be condensed, and the upkeep of IBD patients improved. Following this, the involvement of the patients in the care cycle is also necessary, which could enhance their recovery. For this purpose, there could be several courses and awareness sessions for patients having IBD that could boost their confidence and provide them with a positive prospect of treatment.

## Reference

- Adamina, M., Bonovas, S., Raine, T., Spinelli, A., Warusavitarne, J., Armuzzi, A., & ... & Zmora, O. (2020). ECCO guidelines on therapeutics in Crohn's disease: surgical treatment. *Journal of Crohn's and Colitis*.
- Amiesimaka, O. I., Aluzaita, K., Braund, R., & Schultz, M. (2024). Improving medication adherence levels in inflammatory bowel disease (IBD) patients: A narrative evidence-based review. *Patient Preference and Adherence*, 18, 905–916. <https://doi.org/10.2147/PPA.S383304>
- Artom, M., Czuber-Dochan, W., Sturt, J., & Norton, C. (2017). Cognitive behavioural therapy for the management of inflammatory bowel disease-fatigue with a nested qualitative element: study protocol for a randomised controlled trial. *Trials*, 18(1). <https://doi.org/10.1186/s13063-017-1926-3>
- Barberio, B., Zamani, M., Black, C. J., Savarino, E. V., & Ford, A. C. (2021). Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis. *The Lancet Gastroenterology & Hepatology*.
- Bugwadia, A. K., Reed, S., Finkelstein, A., Park, P., Quinn, C., Dave, S., Jayswal, N., Stewart, G., Kohler, D., Jacobs, N., & Barber, G. E. (2024). Caring for young adult men with inflammatory bowel disease: Clinician and patient perspectives. *Health Care Transitions*, 2, 100043. <https://doi.org/10.1016/j.hctj.2024.100043>
- Ballou S, Keefer L. Psychological Interventions for Irritable Bowel Syndrome and Inflammatory Bowel Diseases. *Clin Transl Gastroenterol*. 2017 Jan 19;8(1):e214. doi: 10.1038/ctg.2016.69. PMID: 28102860; PMCID: PMC5288603.
- Blackwell, J., Saxena, S., Pollock, K., & Smith, G. (2016). Educational needs of patients with inflammatory bowel disease and non-adherence to medical therapy: A qualitative study. *Journal of Crohn's and Colitis*, 10(7), 719-725.
- Beauchamp, A., Talevski, J., Niebauer, J., Gutenberg, J., Kefalianos, E., Mayr, B., Sareban, M., & Kulnik, S. T. (2022). Health literacy interventions for secondary prevention of coronary artery disease: a scoping review. *Open Heart*, 9(1), e001895. <https://doi.org/10.1136/openhrt-2021-001895>
- Byron, C., Cornally, N., Burton, A., & Savage, E. (2020). Challenges of living with and managing inflammatory bowel disease: A meta-synthesis of patients' experiences. *Journal of clinical nursing*, 305-319. doi:<https://doi.org/10.1111/jocn.15080>
- Baars, J. E., Markus, T., Kuipers, E. J., & Van der Woude, C. J. (2019). Patients' perspectives important for symptom management in inflammatory bowel disease: A systematic review of international recommendations. *Journal of Crohn's and Colitis*, 13(8), 934–945. <https://doi.org/10.1093/ecco-jcc/ijj020>
- Bertani, L., Bodini, G., Mumolo, M. G., de Bortoli, N., Ceccarelli, L., Frazzoni, L., Tapete, G., Albano, E., Plaz Torres, M. C., Bellini, M., Savarino, E., Savarino, V., Marchi, S., & Costa, F. (2020). Corticosteroid treatment at diagnosis: An analysis of relapses, disease extension, and colectomy rate in ulcerative colitis. *Digestive Diseases and Sciences*, 65(9), 2397–2402. <https://doi.org/10.1007/s10620-019-05959-y>
- Bonaz, BL (2001). Book Review *Advanced Therapy of Inflammatory Bowel Disease* By Theodore M. Bayless and Stephen B. Hanauer. 670 pp., illustrated. Hamilton, Ont., Canada,

BC Decker, 2001. \$129. 1-55009-122-0. *New England Journal of Medicine*, 345 (1), 72–73. <https://doi.org/10.1056/NEJM200107053450121>

Cleveland, N. K., Torres, J., & Rubin, D. T. (2022). What does disease progression look like in ulcerative colitis, and how might it be prevented? *Gastroenterology*.

Colombel, J. F., D'haens, G., Lee, W. J., Petersson, J., & Panaccione, R. (2020). Outcomes and strategies to support a treat-to-target approach in inflammatory bowel disease: a systematic review. *Journal of Crohn's and Colitis*, 254-266.

Cross, R. K., Langenberg, P., Regueiro, M., Schwartz, D. A., Tracy, J. K., Collins, . . . Quinn, C. C. (2019). A randomized controlled trial of TELEmedicine for patients with inflammatory bowel disease (TELE-IBD). *Official journal of the American College of Gastroenterology | ACG*, 472-482. doi:[https://journals.lww.com/ajg/abstract/2019/03000/a\\_randomized\\_controlled\\_trial\\_of\\_telemedicine\\_for.18.aspx](https://journals.lww.com/ajg/abstract/2019/03000/a_randomized_controlled_trial_of_telemedicine_for.18.aspx)

CL, W., Maass, M., Devine, B., Thornton, T., Grembowski, D., & W Ko, C. (2016). Educational Needs of Patients with Inflammatory Bowel Disease (IBD) and Non-Adherence to Medical Therapy-A Qualitative Study. *Journal of Inflammatory Bowel Diseases & Disorders*, 01(01). <https://doi.org/10.4172/2476-1958.1000106>

Dibley, L., Norton, C., & Hunter, R. (2021). Inflammatory bowel disease: Patients' and professionals' perceptions of shared decision-making. *Journal of Advanced Nursing*, 77(3), 1390-1398.

Daudt, H. M., van Mossel, C., & Scott, S. J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*, 13(48). <https://doi.org/10.1186/1471-2288-13-48>

Dulai, P. S., Jairath, V., Khanna, R., Ma, C., McCarrier, K. P., Martin, M. L., & ... & Sandborn, W. J. (2020). Development of the symptoms and impacts questionnaire for Crohn's disease and ulcerative colitis. *Alimentary pharmacology & therapeutics*.

Daniel J. Stein, a. R. (Red.). (2015). *Inflammatory Bowel Disease A Point of Care Clinical Guide*. Springer International Publishing AG. DOI: <https://doi.org/10.1007/978-3-319-14072-8>

Dewar, B., & Cook, F. (2014). Developing compassion through a relationship-centred model of leadership: Implementing relationship-centred care in a Scottish care home. *Journal of Nursing Management*, 22(5), 629-639. <https://doi.org/10.1111/jonm.12079>

D'Amico, F., Rahier, J. F., Leone, S., Peyrin-Biroulet, L., & Danese, S. (2020). Views of patients with inflammatory bowel disease on the COVID-19 pandemic: a global survey. *The lancet. Gastroenterology & hepatology*, 631. doi: [https://doi.org/10.1016%2FS2468-1253\(20\)30151-5](https://doi.org/10.1016%2FS2468-1253(20)30151-5)

Fawson, S., Dibley, L., Smith, K., Batista, J., Artom, M., Windgassen, S., Syred, J., Moss-Morris, R., & Norton, C. (2021). Developing an Online Program for Self-Management of Fatigue, Pain, and Urgency in Inflammatory Bowel Disease: Patients' Needs and Wants. *Digestive Diseases and Sciences*. <https://doi.org/10.1007/s10620-021-07109-9>

Fiorino, G., Bonovas, S., Danese, S., & Peyrin-Biroulet, L. (2020). Biologic therapies in inflammatory bowel disease: mechanisms, efficacy, and safety. *Gastroenterology*, 159(2), 389-413. <https://doi.org/10.1053/j.gastro.2020.03.052>

Flaubert, J. L., Menestrel, S. L., Williams, D. R., & Wakefield, M. K. (2021). Supporting the health and professional well-being of nurses. In [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov). National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK573902/>

Global Burden of Disease (GBD) 2017 Inflammatory Bowel Disease Collaborators. (2017). The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet Gastroenterology & Hepatology*, 5(1), 17-30. [https://doi.org/10.1016/S2468-1253\(19\)30333-4](https://doi.org/10.1016/S2468-1253(19)30333-4)

Gao, X., Tang, Y., Lei, N., Luo, Y., Chen, P., Liang, C., & ... & Zhang, Y. (2021). Symptoms of anxiety/depression is associated with more aggressive inflammatory bowel disease. *Scientific Reports*.

Golik, M., Kurek, M., Poteralska, A., Bieniek, E., Marynka, A., Pabich, G., ... & Rydzewska, G. (2014). Working Group Guidelines on the nursing roles in caring for patients with Crohn's disease and ulcerative colitis in Poland. *Gastroenterology Review/Przegląd Gastroenterologiczny*, 9(4), 179-193. <https://www.termedia.pl/Working-Group-Guidelines-on-the-nursing-roles-in-caring-for-patients-with-Crohn-s-disease-and-ulcerative-colitis-in-Poland,41,23478,0,1.html>

GBD. (2017). The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet Gastroenterol Hepatol*, 1, 17-30. doi: [https://doi.org/10.1016/S2468-1253\(19\)30333-4](https://doi.org/10.1016/S2468-1253(19)30333-4)

Gajendran, M., Loganathan, P., Catinella, A. P., & Hashash, J. G. (2018). A comprehensive review and update on Crohn's disease. *Disease-a-Month*, 64(2), 20-57. <https://doi.org/10.1016/j.disamonth.2017.07.001>

Gu, Z., Gu, J., & Liu, P. (2024). The effectiveness of continuity of care in patients with inflammatory bowel disease: a systematic review. *BMC Gastroenterology*, 24(1). <https://doi.org/10.1186/s12876-023-03109-3>

Hibi, T., Ishibashi, T., Ikenoue, Y., Yoshihara, R., Nihei, A., & Kobayashi, T. (2020). Ulcerative colitis: disease burden, impact on daily life, and reluctance to consult medical professionals: results from a Japanese internet survey. *Inflammatory intestinal diseases*.

Jones, J., Kennedy, N., & Robinson, A. (2023). What are the unmet needs and most relevant treatment outcomes according to patients with inflammatory bowel disease? *Clinical Gastroenterology*, 57(1), 88-94.

Kang, D.-Y., et al. (2023). Diagnosis of Crohn's disease and ulcerative colitis using the microbiome. *BMC Microbiology*, 23(1), 1–14. <https://doi.org/10.1186/s12866-023-03084-5>

Kennedy, N. A. (2020). The impact of patient involvement on treatment outcomes in inflammatory bowel disease. *Journal of Gastroenterology*, 45(4), 567-575. <https://doi.org/10.1007/s00535-020-01714-x>

Karam, M., Chouinard, M.-C., Poitras, M.-E., Couturier, Y., Vedel, I., Grgurevic, N., & Hudon, C. (2021). Nursing Care Coordination for Patients with Complex Needs in Primary healthcare: a Scoping Review. *International Journal of Integrated Care*, 21(1). <https://doi.org/10.5334/ijic.5518>

- Kavitt, R. T., Lipowska, A. M., Anyane-Yeboah, A., & Gralnek, I. M. (2019). Diagnosis and treatment of peptic ulcer disease. *The American journal of medicine*.
- Kumar, A., Cole, A., Segal, J., Smith, P., & Limdi, J. K. (2022). A review of the therapeutic management of Crohn's disease. *Therapeutic Advances in Gastroenterology*.
- Karadag, P., Morris, B., & Woolfall, K. (2022). The information and support needs of patients living with inflammatory bowel disease: A qualitative study. *Chronic Illness*, 18(2), 356–369. <https://doi.org/10.1177/1742395320968617>
- Kobayashi, T., Siegmund, B., Le Berre, C., Wei, S. C., Ferrante, M., Shen, B., & ... & Hibi, T. (2020). Ulcerative colitis (primer). *Nature Reviews: Disease Primers*.
- Lieng, M. K., Siefkes, H. M., Rosenthal, J. L., Sauers-Ford, H. S., Mouzoon, J. L., Sigal, I. S., Dayal, P., Chen, S. T., McBeth, C. L., Dial, S., Dizon, G., Dannewitz, H. E., Kozycz, K., Jennings-Hill, T. L., Martinson, J. M., Huerta, J. K., Pons, E. A., Vance, N., Warnock, B. N., & Marcin, J. P. (2019). Telemedicine for Interfacility Nurse Handoffs\*. *Pediatric Critical Care Medicine*, 20(9), 832–840. <https://doi.org/10.1097/pcc.0000000000002011>
- Li, J., Mao, R., Kurada, S., Wang, J., Lin, S., Chandra, J., & Rieder, F. (2019). Pathogenesis of fibrostenosing Crohn's disease. *Translational Research*.
- Mirza, R. M., MacKean, G., Shaffer, S. R., Sewitch, M. J., Heisler, C., McLeod, J., Habashi, P., MacDonald, K. V., Barker, K., Nguyen, G. C., & Marshall, D. A. (2022). Patient experiences in the management of inflammatory bowel disease: A qualitative study. *Journal of the Canadian Association of Gastroenterology*, 5(6), 261–270. <https://doi.org/10.1093/jcag/gwac014>
- Mikocka-Walus, A., Andrews, J. M., & Bampton, P. A. (2022). Developing an online program for self-management of fatigue, pain, and urgency in inflammatory bowel disease. *Journal of Gastroenterology & Hepatology*, 37(4), 691-700.
- Mikocka-Walus, A., Massuger, W., Knowles, S. R., Moore, G. T., Buckton, S., Connell, W., Pavli, P., Raven, L., & Andrews, J. M. (2019). Psychological distress is highly (ASKLING, GRAHNQUIST, EKBOM, & FINKEL, 1999) (ASKLING, GRAHNQUIST, EKBOM, & FINKEL, 1999)attitudes. *JGH Open*, 3(4), 227-235. <https://doi.org/10.1002/jgh3.12236>
- Matsuoka, K., Kobayashi, T., Ueno, F., Matsui, T., Hirai, F., Inoue, N., Kato, J., Kobayashi, K., Koganei, K., Kunisaki, R., Motoya, S., Nagahori, M., Nakase, H., Omata, F., Saruta, M., Watanabe, T., Tanaka, T., Kanai, T., Noguchi, Y., ... Watanabe, M. (2018). Evidence-based clinical practice guidelines for inflammatory bowel disease. *Journal of Gastroenterology*, 53(3), 305-353. <https://doi.org/10.1007/s00535-018-1439-1>
- McCormack, B., & McCance, T. (2017). *Person-centred practice in nursing and health care: Theory and practice* (2nd ed.). Wiley-Blackwell.
- Nowlin, C. (2021). Mental health and chronic disease management in inflammatory bowel disease: A person-centered approach. *International Journal of Nursing Studies*, 58(3), 218-225. <https://doi.org/10.1016/j.ijnurstu.2021.06.001>
- National Health Service (NHS). (n.d.). Crohn's disease. NHS. <https://www.nhs.uk/conditions/crohns-disease/>
- Nguyen, N. H., Martinez, I., Atreja, A., Sitapati, A. M., Sandborn, W. J., Ohno-Machado, L., & Singh, S. (2022). Digital health technologies for remote monitoring and management

of inflammatory bowel disease: A systematic review. *The American Journal of Gastroenterology*, 117(1), 78–97. <https://doi.org/10.14309/ajg.0000000000001545>

Naude, C. S.-W. (2023). The effectiveness of mindfulness-based interventions in inflammatory bowel disease: A Systematic Review & Meta-Analysis. *Journal of Psychosomatic Research*, 111232. doi: <https://doi.org/10.1016/j.jpsychores.2023.111232>

O'Connor, M., Bager, P., Duncan, J., Gaarenstroom, J., Younge, L., & N-ECCO Working Group. (2013). N-ECCO consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis. *Journal of Crohn's and Colitis*, 7(9), 744–764. <https://doi.org/10.1016/j.crohns.2013.06.004>

Paparella, S. F. (2016). Person-centered care in 2016: Partnering with patients to improve safety. *Journal of Emergency Nursing*, 42(6), 475-477. <https://doi.org/10.1016/j.jen.2016.09.002>

Plevris, N., & Lees, C. W. (2022). Disease monitoring in inflammatory bowel disease: Evolving principles and possibilities. *Gastroenterology*, 162(5), 1456-1475. <https://doi.org/10.1053/j.gastro.2022.01.024>

Peters, M. D. J., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare*, 13(3), 141-146. <https://doi.org/10.1097/XEB.0000000000000050>

Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A. and McEwen, S. A. (2014), A scoping review of scoping reviews: advancing the approach and enhancing the consistency, *Research Synthesis Methods*, 5, pages 371– 385, DOI: 10.1002/jrsm.1123\

Peters, M. D. J., Marnie, C., Colquhoun, H., Garritty, C. M., Hempel, S., Horsley, T., Langlois, E. V., Lillie, E., O'Brien, K. K., Tunçalp, Özge, Wilson, M. G., Zarin, W., & Tricco, A. C. (2021). Scoping reviews: reinforcing and advancing the methodology and application. *Systematic Reviews*, 10(1), 263. <https://doi.org/10.1186/s13643-021-01821-3>

Plevinsky, J., Greenley, R., & Fishman, L. (2016). Self-management in Patients with Inflammatory Bowel disease: strategies, outcomes, and Integration into Clinical Care. *Clinical and Experimental Gastroenterology*, Volume 9(9), 259–267. <https://doi.org/10.2147/ceg.s106302>

Porter, R. J., Kalla, R., & Ho, G. T. (2020). Ulcerative colitis: Recent advances in the understanding of disease pathogenesis. *F1000Research*.

Popov, J., Farbod, Y., Chauhan, U., Kalantar, M., Hill, L., Armstrong, D., Halder, S., Marshall, J. K., Moayyedi, P., & Kaasalainen, S. (2021). Patients' Experiences and Challenges in Living with Inflammatory Bowel Disease: A Qualitative Approach. *Clinical and Experimental Gastroenterology*, Volume 14(1), 123–131. <https://doi.org/10.2147/ceg.s303688>

Polit, D. F., & Beck, C. T. (2012). *Nursing Research*. London: Wolters Kluwer. P.131-132 and Meta-Syntheses. *Annual review of psychology*, 70, 747–770. <https://doi.org/10.1146/annurev-psych-010418-102803>

- Polit, D.F. and Beck, C.T. (2017) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th Edition, Wolters Kluwer Health, Philadelphia, <https://doi.org/10.1016/j.iccn.2015.01.005>
- Perler, B. K., Ungaro, R., Baird, G., Mallette, M., Bright, R., Shah, S., & ... & Sands, B. E. (2019). Presenting symptoms in inflammatory bowel disease: descriptive analysis of a community-based inception cohort. *BMC gastroenterology*.
- Quinn, C. C., Chard, S., Roth, E. G., Eckert, J. K., Russman, K. M., & Cross, R. K. (2019). The Telemedicine for Patients With Inflammatory Bowel Disease (TELE-IBD) Clinical Trial: Qualitative Assessment of Participants' Perceptions. *Journal of Medical Internet Research*, 21(6), e14165. <https://doi.org/10.2196/14165>
- Richard, L., Noller, G., Derrett, S., Sullivan, T., Doolan-Noble, F., McCombie, A., Schultz, M., Ho, C., & Stokes, T. (2020). Patients' accounts of living with and managing inflammatory bowel disease in rural southern New Zealand: A qualitative study. *BMJ Open*, 10(11), e041789. <https://doi.org/10.1136/bmjopen-2020-041789>
- Rosso, C., Aaron, A. A., Armandi, A., Caviglia, G. P., Venero, M., Saracco, G. M., Astegiano, M., Bugianesi, E., & Ribaldone, D. G. (2021). Inflammatory Bowel Disease Nurse—Practical Messages. *Nursing Reports*, 11(2), 229–241. <https://doi.org/10.3390/nursrep11020023>
- Roda, G. C., S., K., P. G., A., M., P., R., S., & A., .. &. (2020). Crohn's disease. *Nature Reviews Disease Primers*.
- Ross, P., & Zaidi, N. (den 25 July 2019). National Library of Medicine. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6684501/>
- Sulz, M. C., Burri, E., Michetti, P., Rogler, G., Peyrin-Biroulet, L., & Seibold, F. (2020). Treatment algorithms for Crohn's disease. *Digestion*.
- Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). *How to Do a Systematic Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses*,
- Stein, D. J., & Shaker, R. (Eds.). (2015). *Inflammatory bowel disease: A point of care clinical guide*. Springer International Publishing AG. ProQuest Ebook Central. <https://ebookcentral-proquest-com.ezproxy.novia.fi/lib/novia-ebooks/detail.action?docID=2094243>
- Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centered care: A conceptual framework. *Health Expectations*, 21(2), 429-440. <https://doi.org/10.1111/hex.12640>
- Szabo, H. (2019). Genetic factors in inflammatory bowel diseases: Implications for personalized medicine. *World Journal of Gastroenterology*, 25(37), 5461–5475. <https://doi.org/10.3748/wjg.v25.i37.5461>
- Singh, S., Qian, A. S., Nguyen, N. H., Ho, M., S. K., L, J., . . . Ma, C. (2022). Trends in U.S. Health Care Spending on Inflammatory Bowel Diseases. *Inflammatory bowel diseases*, 3, 364–372. doi: <https://doi.org/10.1093/ibd/izab074>
- Saleh, M. O., Eshah, N. F., & Rayan, A. H. (2022). Empowerment Predicting Nurses' Work Motivation and Occupational Mental Health. *SAGE Open Nursing*, 8(1), 237796082210768. <https://doi.org/10.1177/23779608221076811>

Stein, D. J., & Shaker, R. (Eds.). (2015). *Inflammatory bowel disease: A point of care clinical guide*. Springer International Publishing AG.

Trivedi, H., Avrit, T. A., Chan, L., Burchette, D. M., & Rathore, R. (2022). The Benefits of Integrative Medicine in the Management of Chronic Pain: A Review. *Cureus*, 14(10). <https://doi.org/10.7759/cureus.29963>

Torres, J., Bonovas, S., Doherty, G., Kucharzik, T., Gisbert, J. P., Raine, T., & ... & Fiorino, G. (2020). ECCO guidelines on therapeutics in Crohn's disease: medical treatment. *Journal of Crohn's and Colitis*.

Taft, T. H., Ballou, S., Bedell, A., & Lincenberg, D. (2017). Psychological considerations and interventions in inflammatory bowel disease patient care. *Gastroenterology Clinics of North America*, 46(4), 847–858. <https://doi.org/10.1016/j.gtc.2017.08.007>

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., ... & Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467-473. <https://doi.org/10.7326/M18-0850>

Wang, Y. F., Zhang, H., & Ouyang, Q. (2007). Clinical manifestations of inflammatory bowel disease: East and West differences. *Journal of Digestive Diseases*, 8(3), 121–127. <https://doi.org/10.1111/j.1443-9573.2007.00296.x>

Wickman, U. L.-U. (2019). Development of a self-care questionnaire for clinical assessment of self-care in patients with inflammatory bowel disease: A psychometric evaluation. *International Journal of Nursing Studies*, 1-7. doi: <https://doi.org/10.1016/j.ijnurstu.2018.08.016>

Wu, Q., Zhu, P., Liu, X., Chen, C., Ji, Q., & Gu, Q. (2022). The impact of family function on mental health status in patients with inflammatory bowel disease: The mediating role of self-esteem. *Frontiers in Psychiatry*, 13, 1007318. <https://doi.org/10.3389/fpsy.2022.1007318>

Wilkinson, B., McCartney, S., & Price, A. (2018). Nurses are critical in aiding patients transitioning to biosimilars in inflammatory bowel disease: Education and communication strategies. *Gastroenterology Nursing*, 41(5), 367-373.

Yin Ting-Ting, Wen-Jing, T., Yi-Ting, L., Xu Wen-Jing, & Xu Gui-Hua. (2023). “Eating is like experiencing a gamble”: A qualitative study exploring the dietary decision-making process in adults with inflammatory bowel disease. *Health Expectations*, 27(1). <https://doi.org/10.1111/hex.13873>

Zonderman, A. B., & Vender, R. (2000). Crohn's disease and the challenges of management. *Journal of Gastrointestinal Diseases*, 12(3), 245-257.

## 9 Appendixes

Sl. No.	Title	Author and Year of Publication	Aim	Result
1	Patient Strategies for Managing the Vicious Cycle of Fatigue, Pain and Urgency in Inflammatory Bowel Disease: Impact, Planning, and Support	Lesley Dibley, Bernadette Khoshaba, Micol Artom, Victoria Van Loo, Louise Sweeney, Jonathan Syred, Sula Windgassen, Georgia Mofatt, Christine Norton and members of the IBD-BOOST PPI team (2020)	To understand how people with IBD experience and self-manage these symptoms and to inform the future development of an online self-management program.	This study discusses how Fatigue, pain, and urgency are troublesome for patients, especially in combination, suggesting that clinicians should address these simultaneously. Participants reported several strategies for self-management, providing patient-focused evidence to inform the future development of a self-management intervention program.
2	Working Group Guidelines on the nursing roles in caring for patients with Crohn's disease and ulcerative colitis in Poland	Magdalena Golik, Marzena Kurek , Aneta Poteralska , Ewa Bieniek, Anna Marynka , Grażyna Pabich , Ariel Liebert, Maria Kłopočka, Grażyna Rydzewska (2014)	The research seeks to pinpoint nurses' duties and methods when caring for patients with bowel disease (IBDs) in line with European standards to promote the best possible results for patients.	The research explores creating guidelines for healthcare in Poland that focus on nursing roles and conditions related to IBD care in the country's context. It highlights the significance of a strategy to enhance the quality of care and advocates for collaboration with entities to elevate nursing standards.

3	Systematic review: Psychosocial factors associated with pain in inflammatory bowel disease	L. Sweeney, R. Moss-Morris, W. Czuber-Dochan, L. Meade, G. Chumbley, C. Norton; published in 2018.	This study aims to explore the connection between social factors and pain in adults with bowel disease (IBD).	The report highlights factors, like depression and anxiety, that can affect pain in IBD patients. It recommends exploring ways to measure pain for patient results.
4	Developing an Online Program for Self-Management of Fatigue, Pain, and Urgency in Inflammatory Bowel Disease: Patients' Needs and Wants	Sophie Fawson, Lesley Dibley, Kaylee Smith, Joanna Batista, Micol Artom, Sula Windgassen, Jonathan Syred, Rona Moss-Morris, Christine Norton; published in 2022.	The goal was to explore the requirements and choices of patients regarding an internet-based self-care program for managing symptoms of IBD, such as tiredness, pain, and urgency.	The research underscores the importance to patients of having easy-to-access assistance that includes features for monitoring symptoms and handling medication regimens. This feedback guided the creation of the IBD BOOST program, which is presently in the testing phase.
5	The effectiveness of continuity of care in patients with inflammatory bowel disease: a systematic review	Zijun Gu, Junyi Gu, and Ping Liu; published in 2024	Exploring how consistency in healthcare influences the well-being of individuals with bowel disease (IBD) with a focus on how it affects their quality of life and remission rates, as well as their frequency of outpatient visits and adherence to medication.	The assessment suggests that maintaining care could lower the number of outpatient appointments and enhance adherence to medication among individuals with bowel disease (IBD). However, it does not indicate any effect on the quality of life or remission rates for these patients.

6	Disease Monitoring in Inflammatory Bowel Disease: Evolving Principles and Possibilities	Nikolas Plevris and Charlie W. Lees; published in 2022	Exploring the tools and potential advancements in tracking disease progression in patients with bowel disease (IBD), particularly emphasizing the "targeted treatment strategy."	The research highlights the significance of monitoring diseases by utilizing biomarkers and patient feedback to enhance the long-term management of IBD (bowel disease).
7	Digital Health Technologies for Remote Monitoring and Management of Inflammatory Bowel Disease: A Systematic Review	Nghia H. Nguyen, Ivonne Martinez, Ashish Atreja, Amy M. Sitapati, William J. Sandborn, Lucila Ohno-Machado, Siddharth Singh; published in 2022	Examining the impact of health solutions on managing IBD by evaluating their effectiveness in disease monitoring accuracy and treatment compliance, as well as their influence on quality of life and healthcare resource usage.	Digital health solutions have been suggested to reduce healthcare expenses, although there is no proof of enhancing adherence or quality of life compared to care practices.
8	The impact of family function on mental health status in patients with inflammatory bowel disease: The mediating role of self-esteem	Qiwei Wu, Pingting Zhu, Xinyi Liu, Chen Chen, Qiaoying Ji, Qiaohua Gu; published in 2022.	The goal was to explore the influence of family dynamics on the well-being of individuals with bowel disease (IBD), focusing on how self-esteem plays a role in mediating the effects of depression and anxiety.	The research shows that having support from family members can have an impact on one's self-esteem. This can lead to levels of depression and anxiety in patients with Inflammatory Bowel Disease (IBD). It indicates that interventions focusing on boosting self-esteem could potentially enhance well-being.

<b>9</b>	Improving Medication Adherence Levels in Inflammatory Bowel Disease (IBD) Patients: A Narrative Evidence-Based Review	Breniokibo Ibifubara Amiesimaka, Kristina Aluzaitė, Rhiannon Braund, Michael Schultz; published in 2024.	This study evaluated various interventions to enhance medication adherence among IBD patients.	Educational and behavioural interventions have varying outcomes. Multifaceted interventions are found to be successful in addressing the factors impacting medication adherence and managing IBD.
<b>10</b>	Patients' Experiences and Challenges in Living with Inflammatory Bowel Disease: A Qualitative Approach	Jelena Popov, Yasamin Farbod, Usha Chauhan, Mona Kalantar, Lee Hill, David Armstrong, Smita Halder, John K. Marshall, Paul Moayyedi, Sharon Kaasalainen; published in 2021.	The purpose of this paper is to delve into the societal hurdles encountered by individuals with IBD and propose strategies for enhancing their quality of life.	The research highlights themes concerning the effects on individuals and families. It also discusses the challenges and the importance of receiving quality care. The study recommends that better communication with healthcare professionals and access to support services could improve patients' experiences.
<b>11</b>	N-ECCO Consensus Statements on the European Nursing Roles in Caring for Patients with Crohn's Disease or Ulcerative Colitis	M. O'Connor, P. Bager, J. Duncan, J. Gaarenstroom, L. Younge, et al.; published in 2013.	The article defines nursing roles in caring for IBD patients across Europe.	This article emphasizes nursing procedures to advocate for a high-quality method of caring for IBD patients within healthcare facilities across Europe.

<b>12</b>	Self-Management in Patients with Inflammatory Bowel Disease: Strategies, Outcomes, and Integration into Clinical Care	Jill M. Plevinsky, Rachel N. Greenley, Laurie N. Fishman; published in 2016.	It Explores ways to manage IBD and its incorporation into treatment and support effectively.	It discusses the importance of self-care education and highlights the significance of the relationship between patients and healthcare providers in enhancing adherence and results.
<b>13</b>	Patient Experiences in the Management of Inflammatory Bowel Disease: A Qualitative Study	M. Mirza, Gail MacKean, Seth R. Shaffer, et al.; published in 2022	This article explores IBD patients' experiences and perspectives on healthcare delivery in Canada	Identifies gaps in access, the need for multidisciplinary care, patients' psychosocial needs, and the importance of patient-centered approaches.
<b>14</b>	The Information and Support Needs of Patients Living with Inflammatory Bowel Disease: A Qualitative Study	Paige Karadag, Beth Morris, Kerry Woolfall; published in 2022	The informational and emotional support needs of IBD patients.	Implies that providing understanding information and compassionate healthcare interactions are components.
<b>15</b>	Inflammatory Bowel Disease Nurse—Practical Messages	Chiara Rosso, Alami Aroussi Aaron, Angelo Armandi, et al.; published in 2021.	The role and benefits of IBD nurses within multidisciplinary teams.	The role of IBD nurses is to improve patient care by facilitating communication between patients and physicians by addressing their clinical and educational requirements.
<b>16</b>	Caring for Young Adult Men with Inflammatory Bowel Disease: Clinician and Patient Perspectives	Amy K. Bugwadia, Sydney Reed, Adam Finkelstein, et al.; published in 2024.	This addresses the unique challenges faced by young adult men with IBD.	Highlights the importance of identifying psychosocial factors, including sexual

				and reproductive health, and provides recommendations for tailored support
<b>17</b>	Patients' Accounts of Living with and Managing Inflammatory Bowel Disease in Rural Southern New Zealand	Lauralie Richard, Geoff Noller, Sarah Derrett, et al.; published in 2020.	The experiences of IBD patients in rural New Zealand.	Identifies unique rural challenges in accessing IBD care and the importance of telemedicine for better support.
<b>18</b>	Eating is Like Experiencing a Gamble: A Qualitative Study Exploring the Dietary Decision-Making Process in Adults with Inflammatory Bowel Disease	Yin Ting-Ting, Tu Wen-Jing, Li Yi-Ting, et al.; published in 2023	It explores dietary decision-making processes in IBD patients.	The result shows that dietary decisions are influenced by symptom assessment, past experiences, and cultural beliefs. It also highlighted the need for better dietary guidance.
<b>19</b>	The Telemedicine for Patients with Inflammatory Bowel Disease (TELE-IBD) Clinical Trial: Qualitative Assessment of Participants' Perceptions	Charlene Connolly Quinn, Sarah Chard, Erin G Roth, et al.; published in 2019.	To assess patient perceptions of telemedicine for IBD management.	The result shows that telemedicine helped IBD patients monitor symptoms and feel connected to their healthcare providers.
<b>20</b>	Psychological Considerations and Interventions in Inflammatory Bowel Disease Patient Care	H. Taft, PsyD; Sarah Ballou, PhD; Alyse Bedell, MS; Devin Lincenberg, PsyD	To review the psychosocial challenges in inflammatory bowel disease (IBD)	Shows psychological distress in IBD patients, disease impact, treatment concerns, and stigma. CBT Intervention