Spring 4-4-2022

UNCOVERING THE EDUCATIONAL AND SELF MANAGEMENT NEED IN PEOPLE WITH INFLAMMATORY BOWEL DISEASE

Zachary Palumbo
Pittsburg State University, zpalumbo@gus.pittstate.edu

UNCOVERING THE EDUCATIONAL AND SELF MANAGEMENT NEED IN PEOPLE WITH INFLAMMATORY BOWEL DISEASE

Scholarly Project Submitted to the Graduate School
in Partial Fulfillment of the Requirements
for the Degree of
Doctor of Nursing Practice

Zac Palumbo, BSN, RN

Pittsburg State University

Pittsburg, Kansas

May, 2022

UNCOVERING THE EDUCATIONAL AND SELF MANAGEMENT NEED IN PEOPLE WITH INFLAMMATORY BOWEL DISEASE

An Abstract of the Scholarly Project by
Zachary Palumbo

The purpose of the study was to assess the current knowledge of inflammatory bowel disease (IBD), self-management skills, and resources for IBD in people suffering from the condition. Self-management skills and education have been shown, along with medical treatment, to show improvements in symptom activity and overall quality of life (Conley & Redeker, 2016).The study used Orem's Self-Care deficit theory as the theoretical framework. A mixed methods design was chosen for this particular study. The project provided an educational video and a pre and post-survey through email. The questionnaire and pre-test (Appendix A) was given before the education, and Appendix C was given after receiving the education (Appendix B). The information obtained was used to assess the individuals' knowledge and self-management of IBD. Inclusion criteria: participants were 18 years and older, able to read and understand English, and have a diagnosis of Crohn's disease or ulcerative colitis. Exclusion criteria: individuals under the age of 18, not able to read and understand English or does not have a medical diagnosis of Crohn's disease or ulcerative colitis. The study demonstrated that people with IBD are willing to learn more and participate in similar studies. The study concluded that the knowledge over medications and management increased (medications: 28% to 33.6%) with the educational resource. The study demographics were found to be unbiased towards sex, race or disease process. The study also looked at qualitative data providing different resources, and needs wanted by the participants.

TABLE OF CONTENTS

CHAPTER PAGE

I. INTRODUCTION....1

Introduction....1
Description of Clinical Problem....2
Significance....4
Purpose....5
Theoretical Framework....6
Project Questions....9
Definition of Key Terms....10
Logic Model....11
Summary....13

II. REVIEW OF THE LITERATURE....14

Inflammatory Bowel Disease....15
Complications....16
Recommendation from IBD Patients....18
Diagnosis and Treatment....20
Support for IBD Patients....24
Barriers....26
Summary....27

III. METHODOLOGY....28

Project Design....28
Sample/Target Population....29
Inclusion and Exclusion Criteria....29
Data Collection....29
Protection of Human Subjects....30
Analytical Methods....31
Timeline....31
Strengths and Weaknesses....31
Summary....32

IV. EVALUATION RESULTS....33

Description of Population....33
Analysis of Project Questions....34
Research Question One....34
Research Question Two....38
Research Question Three....40
Research Question Four....42

CHAPTER.....PAGE

Research Question Five.....45
Research Question Six.....46
Summary.....47

V.DISCUSSION.....48

Relationship of Outcomes to Research.....48
Observations.....52
Evaluation of Theoretical Framework.....53
Evaluation of Logic Model.....54
Limitations.....54
Implications for Future Projects and/or Research.....55
Implications for Practice/Health Policy/Education.....55
Conclusion.....56

REFERENCES.....57

APPENDICES.....61
Appendix A.....62
Appendix B.....66
Appendix C.....69

LIST OF TABLES

TABLE..... PAGE

I. Number of Correct Answers.....36

LIST OF FIGURES

FIGURE.....PAGE

1. IBD and Nursing Intervention.....9
2. Logic Model.....12
1.Current Knowledge on Management Pre-test.....36
2. Current Knowledge on Management Post-test.....37
3. Knowledge of Healthy Diet Pre-test.....37
4. Knowledge of Healthy Diet Post-test.....38
5. Current Medication Knowledge Pre-test.....40
6. Current Medication Knowledge Post-test.....41
A. Answers to Question #8 Pre-test.....42
B. Answers to Question #8 Post-test.....42
C. Age Range.....43
D. Gender Percentage.....44
E. Diversity of Participants.....44
F. Urban vs. Rural Participants.....44
G. Participant's Family History.....45
H. Participant's Diagnosis.....46

Chapter I

Introduction

Inflammatory bowel disease is associated with inflammation of the gastrointestinal tract that causes decreased quality of life in those that endure it. The term inflammatory bowel disease (IBD) is an umbrella term that encompasses Crohn's disease and ulcerative colitis (Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016). The two disease processes are different in their pathophysiology, though they both affect the gastrointestinal tract and share similar symptoms.

The CDC estimated around 3.1 million United States adults were diagnosed with inflammatory bowel disease in 2015 (Dahlhamer et. al, 2016). In 1999, the estimated number of United States adults with inflammatory bowel disease was 1.8 million. The increase percentage rate in the U.S. was from 0.9 percent to 1.3 percent and differed in sociodemographic categories, such as ethnicity, education level and poverty status (Dahlhamer et. al, 2016). The number of people diagnosed with IBD has increased significantly since 1999. The increasing numbers have an impact on the nursing system. The average hospital cost for a hospital stay for a patient with ulcerative colitis is $13,412 (Crohn's and Colitis Foundation of America, 2014). The rate of hospitalization increased from 44.2 to 59.7 per 1,000 population from 2003 to 2013 (CDC, 2019). Overall, the

increased incidence and hospitalization of these patients can cost the patients and the health care system a large amount of money.

The impact of education on IBD has been studied over the years. However, the number of resources to obtain education for individuals in Southeast Kansas is limited to a certain number of clinics or specialists in Joplin, MO. Resources are limited throughout other rural areas in the United States. Education has been assessed and found to be a need and want of patients. People with IBD want more in-depth knowledge about their diseases, such as knowledge related to the course of the disease, complications of IBD, and how to manage social life with IBD (Lesnovska, Borjeson, Hjortswang, & Frisman, 2013).

The education of people suffering from IBD also includes self-management. The self-management tools and skills allows for patients to care for themselves and their symptoms at home, keep themselves in remission, and avoid hospital stays when possible (Conley & Redeker, 2016).

This study will discuss the issues with IBD, self-management and how the study was conducted. The results of the study will also be discussed.

Description of Clinical Problem

Resources for patients to obtain information on their IBD is limited in places throughout the United States. Patients receive education from doctors' offices (specialists), health clinics, or if hospitalized. The limited number of places to obtain outpatient education leads people to use the main resource available, the internet. Though most individuals use the internet for information, it is the least trusted medium of education (McDermott et al., 2018). Patients may have a difficult time sorting out the true

facts and have access to only a few places for help. The limited number of education resources for people with IBD limits their ability to care for themselves properly.

IBD is a condition that affects the gastrointestinal tract. The cause of IBD is still unknown. Inflammatory bowel disease can be divided into two different conditions, Crohn's disease and ulcerative colitis. Ulcerative colitis causes long lasting inflammation and ulcerations of the lining of the colon, also known as the large intestine to the rectum. Crohn's disease can cause inflammation throughout the digestive tract, from the mouth to the rectum. The inflammation with Crohn's disease also can spread into deeper tissue than just the lining of the intestines (Mayo Clinic, 2019). The Mayo Clinic (2019) shows that the two conditions share similar symptoms of blood being in stool, diarrhea, cramping and abdominal pain, weight loss and poor appetite.

Diagnosis of IBD is done with labs for occult blood in the stool, anemia and infection. Once other causes are ruled out, endoscopic procedures, such as a colonoscopy or sigmoidoscopy, will be done for diagnosis. The procedures allow for the actual site of the problem to be visualized by a small camera. Imaging such as x-rays and computerized tomography (CT) scans can be done to assist in diagnosis. Imaging is a less invasive way of viewing any issues with the bowel (Mayo Clinic, 2019).

There is no cure for IBD. According to the Mayo Clinic (2019), management of IBD is focused on reducing inflammation, damage, and symptom relief and remission, if possible. Treatment can include use of multiple types of medications to achieve remission. Anti-inflammatory medications are used first; these include steroids and aminosalicylates. The type of anti-inflammatory medication often depends on the location of the inflammation. Immune system suppressors are the more potent

medications. The immune suppressors work in varied ways to suppress the immune response/chemicals, which are inducing the inflammation (Mayo Clinic, 2019). Other medications can be used to relieve symptoms, such as anti-diarrheal medications, pain relivers, iron, calcium, and vitamin D supplements. IBD often affects absorption of nutrients, calling for the need of nutritional support and special diets to rest and protect the bowel. In severe cases, patients will have to under-go surgery. Surgery can cure ulcerative colitis by removing the colon to the rectum however, relief from surgery will only last for a while with Crohn's disease if symptoms are not controlled (Mayo Clinic, 2019).

Management of IBD is not just done at the specialist's office or clinic but at home every day by the people suffering from the disorder. The concern has been voiced by people suffering from IBD that they often feel they lack enough information about their disease to manage their symptoms at home with confidence (Lesnovska, et al., 2013). More resources and education are needed to help them manage their IBD and improve their quality of life.

Significance

The Centers for Disease Control and Prevention (CDC) (2019) estimated that approximately three million United States adults have been diagnosed with IBD. The disease is associated with painful symptoms, increased hospitalizations and poor quality of life. Crohn's disease and ulcerative colitis are complicated disease conditions with multiple triggers for worsening symptoms and varying symptoms among individuals (CDC, 2019). People with IBD have stated they need more education than the 15 or 20 minutes that they receive at appointments (Lesnovska et al., 2013). Patients deserve to

have the resources/education to assist them. This is why more educational resources should be available for these people.

It is the responsibility of healthcare providers to ensure that patients are educated properly about their conditions and have the resources to manage their conditions at home. The education and self-management resources available to these patients should be increased. This study focused on creating a resource for individuals suffering from IBD. The resource was an educational session held to educate the people with IBD, as well as friends and family, on the disease, and self-management skills to assist them at home, something those suffering from IBD state as a need. The study examined the available educational resources for those with IBD. The topics gave a good foundation for the creation of resources for IBD patients.

Purpose

The purpose of the study was to assess the current knowledge of IBD, self-management skills, and resources for IBD in people suffering from the condition. Self-management skills and education have been shown, along with medical treatment, to show improvements in symptom activity and overall quality of life (Conley & Redeker, 2016). People with chronic health conditions, such as IBD, need to have resources available to them to assist them with their needs. Evaluation of the available resources to these patients suffering from IBD is a priority. The limited number of educational resources for these patients make the creation of an education resource a priority. The increase in education has also been shown to improve psychiatric symptoms from IBD, such as decreased anxiety with the disease which improves quality of life with patients

(Conley & Redeker, 2016). Self-management education was found to increase in health-related quality of life, with self-management programs being more successful than other interventions (Conley & Redeker, 2016). The creation of an educational program for patients with IBD could also improve patients' symptoms and quality of life by providing proper educational and self-management support.

This study inquired from IBD patients and previous studies to sort out proper and needed topics for people with IBD. The topics were arranged into an educational presentation for people with inflammatory bowel disease. The educational presentation (Appendix B) was evaluated after the presentation with a post test (Appendix C). The participants were tested on their knowledge before and after the presentation. The overall aim was to demonstrate the support for self-management and educational resources in the management of IBD. The main areas focused on were:

- Inflammatory bowel disease knowledge
- Self-management skills
- Feeling towards the disease, treatment and resources

Theoretical Framework: Orem's Self-Care Deficit Nursing Theory

Orem's self-care deficit theory was chosen to guide this project. The theory was written by Dorothea Orem between 1959 and 2001 (Gonzalo, 2014). The theory is based on the principle that people want to care for themselves, if possible. The major assumptions of the theory that correlate with the project include (a) people must be self-reliant and engage in constant learning and communication to adapt to their needs, (b) people as individuals exercise discovering and developing new ways to identify needs for themselves or others, and (c) knowledge of health issues can assist in a person's self-care.

The assumptions listed correlate with the project in relation to people caring for themselves at home and needing the proper information to properly care for themselves.

Orem's self-care deficit theory contains three interrelated theories: the theory of self-care, the self-care deficit theory, and the theory of nursing systems. The theory of self-care focuses on the ability of individuals to perform activities to maintain their health and well-being. The activities are called self-care requisites and focus on processes of functioning in everyday life, such as having sufficient intake, balanced activity with rest, and adequate socialization (Gonzalo, 2014). The self-care deficit focuses on when nursing is needed to assist the individual in maintaining or improving self-care. The need could be from the individual being incapable or limited in resources. Orem's theory identifies five methods of helping. Four of the methods correlate to this project: guiding others, supporting another, teaching another, and providing an environment promoting personal development (Gonzalo, 2014).

The significance of Orem's theory to this project is identifying the proper time and the proper interventions to assist patients in achieving the best health outcome. The theory lays a good foundation and framework to assist in educating patients suffering from IBD. Orem's model for her theory is very simple to follow and gives a clear picture of the key concepts in this theory and how they relate to each other. The model (Figure 1 below) illustrates the relationship of the educational program with patients suffering from IBD. The process is initiated when the self-care need exceeds the individual's self-care agency. The model below depicts the self-care agency as the individual's age, gender, education, and disability. The self-care lists the basic needs of the individual, and the self-care demand is depicted at the condition that the patient has been diagnosed with,

such as Crohn's or ulcerative colitis. The nursing agency to assist in the demand is the education program to be held for the patient. Orem's self-care deficit theory was used to help guide this project in assessing the patients' needs and providing the proper intervention for them. The theory along with the project was used to create an educational program to inform and support patients with IBD.

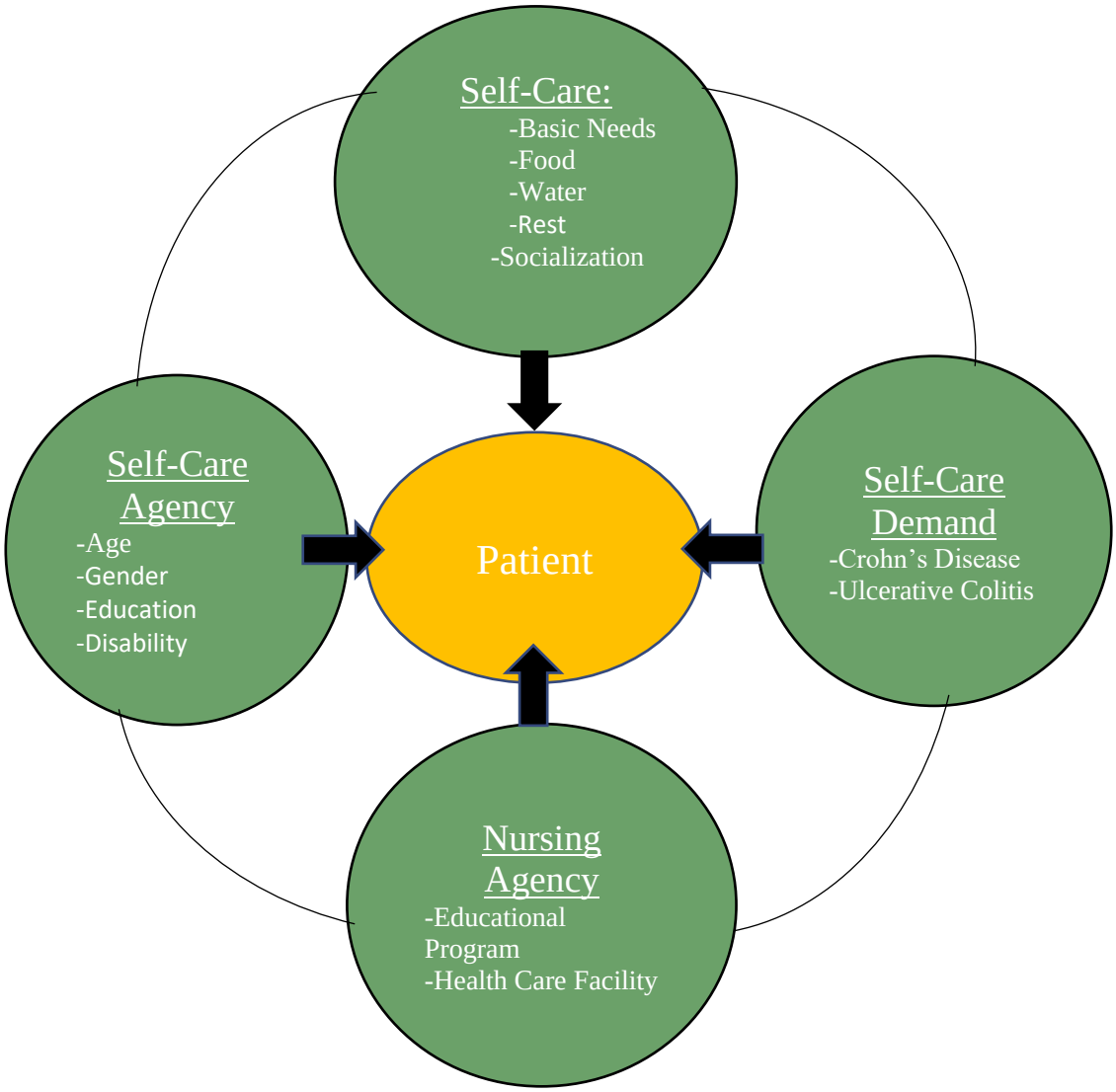


Figure 1. IBD and Nursing Intervention (Adapted from Dorothea Orem's Self-Care Deficit Theory Conceptual Model). (Gonzalo, 2014)

Project Questions

Inflammatory bowel disease is a complex condition that people suffer from and can cause multiple symptoms. The complexity of the disease raises more questions to be assessed by the project itself. The questions were to evaluate not only the patient's

symptoms and knowledge about IBD but also to assess the educational program itself to improve the resources:

1. Does IBD education improve participants' knowledge on symptom management?
2. Does IBD education improve confidence of self-management?
3. What are participants' confidence levels with their medications for IBD?
4. What are the participants' demographics regarding ethnicity, age, gender, and rural vs. urban?
5. What is the participant's diagnosis (Crohn's or ulcerative colitis)?
6. What are some resources people with IBD would want?

Definition of Key Terms

The key terms need to be understood for the majority of the project to be comprehended as needed. The key terms are clarified here to permit understanding.

Colonoscopy: A colonoscopy is an exam used to detect abnormalities in the large intestine and rectum. During a colonoscopy, a flexible tube is inserted into the rectum. A tiny camera on the tip of the scope allows the doctor to view the inside of the colon (Mayo Clinic, 2019, p. 5).

Crohn's Disease (CD): "Inflammation may reach through the multiple layers of the walls of the gastrointestinal tract. Damaged areas appear in patches that are next to areas of healthy tissue." Crohn's can affect any part of the gastrointestinal tract from the mouth down to the anus, however, it is mostly found in the small intestines (CDC, 2019, p. 2-3).

Gastroenterologist: "A Gastroenterologist is a physician with dedicated training management of diseases of the gastrointestinal tract and liver" (American College of Gastroenterology, 2019, p. 2).

Gastrointestinal Tract (GI tract): "is a series of hollow organs joined in a long, twisting tube from the mouth to the anus. The hollow organs that make up the GI tract are the mouth, esophagus, stomach, small intestine, large intestine, and anus" (National Institute of Diabetes and Digestive and Kidney Diseases, 2019, pp. 1-2).

Inflammatory Bowel Disease (IBD): "is a term for two conditions (Crohn's disease and ulcerative colitis) that are characterized by chronic inflammation of the gastrointestinal (GI) tract." The inflammation causes damage to the gastrointestinal tract (Centers for Disease Control and Prevention, 2019, p. 2-3).

Self-Management: "is a dynamic, interactive process that captures the complexity of living with chronic illness in the context of daily life" (Conley & Redeker, 2016, p. 1).

Ulcerative Colitis (UC): "Inflammation is present only in the innermost layer of the lining of the colon. Damaged areas are continuous usually starting at the rectum and spreading further into the colon" (CDC, 2019, p. 2-3).

Logic Model

The current IBD education design and anticipated outcomes are illustrated in the diagram below (Figure 2). The diagram visualizes organization of the project from the antecedents of the education program to the outcomes and lists the different types of examples. The antecedents contain the patients' demographics and baseline knowledge of their condition. The diagram begins at the left looking at the available resources received at the education program. The end of the diagram shows the outcomes, such as behavior.

The project provided an educational video through email. The patients were emailed surveys before and after the program to assess their knowledge of IBD, self-management skills with IBD, and educational needs. The educational program was

intended to assist patients to better self-manage their symptoms and themselves at home. The intervention was predicted to assist patients to feel more confident with their condition and to possibly avoid hospitalization. The outcomes of the diagram are listed as to what was intended to occur after the patients attend the educational program.

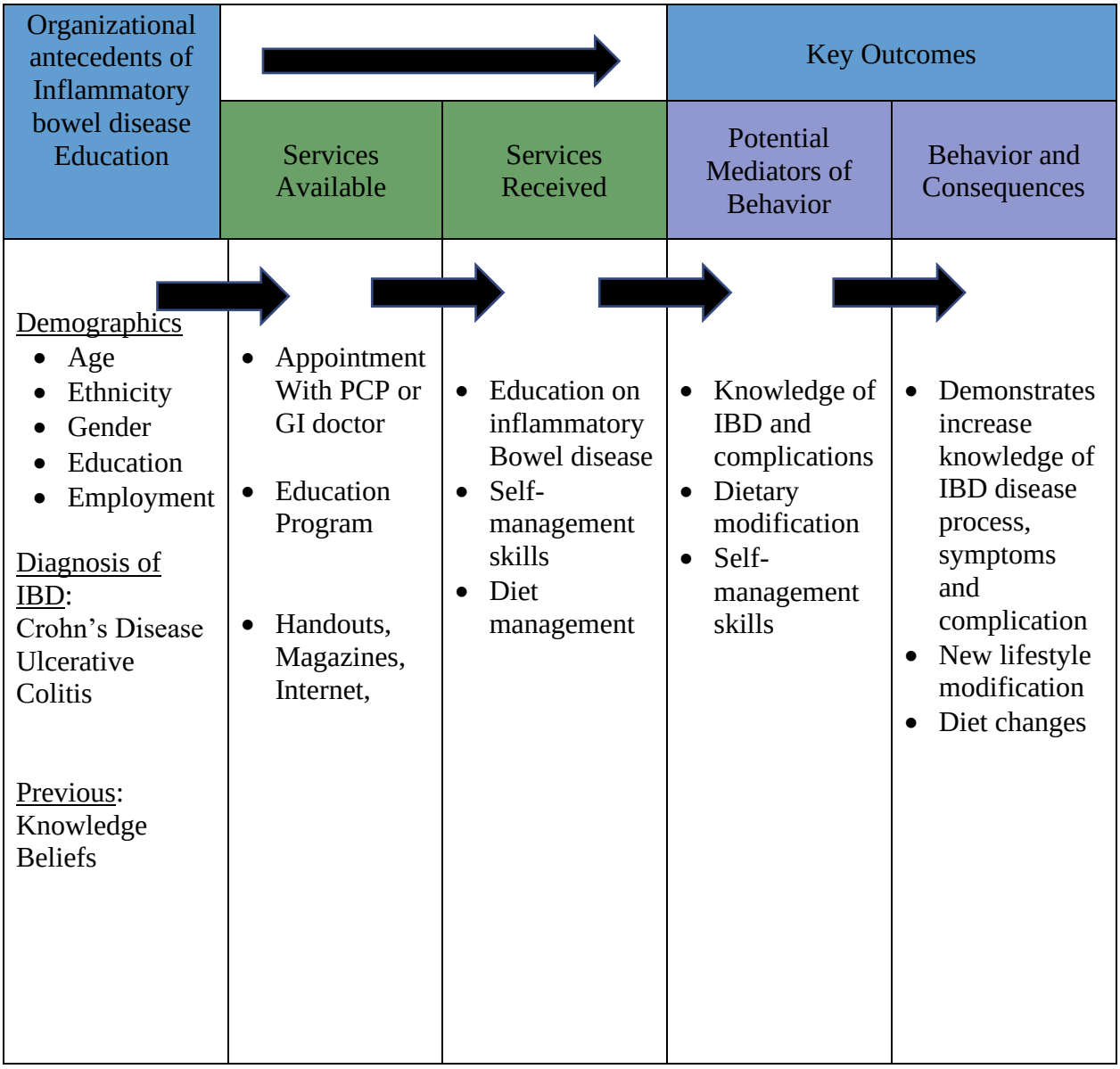


Figure 2. Logic Model

Summary

Inflammatory bowel disease is a growing condition in the United States, increasing to three million people. The condition leaves patients suffering from diarrhea, malabsorption, abdominal cramping and pain (CDC, 2019). The condition can even leave patients struggling with everyday life, such as working and traveling. Patients do not have many resources after their primary care doctor and gastroenterologist. Some of the closest resources for those suffering from IBD in Southeast Kansas are in Joplin, MO (around 33 miles away) and Kansas City, MO, (around 122 miles away) (Crohn's and Colitis Foundation, 2019). The travel time to these two larger cities is around 45 minutes to an hour for a Joplin trip and around two hours to Kansas City each way. This is usually the story for rural areas and small towns in the United States. The challenge to make these appointments can be very difficult to individuals. The lack of resources leaves the patients with IBD vulnerable to lack of education, self-management, and could increase the need for doctor visits and hospitalizations.

An educational program was implemented and tested. People suffering from inflammatory bowel disease were assessed before and after an educational program. The program was presented with education about IBD and self-management skills to help manage their condition. Education in IBD and self-management skills has shown to assist people with IBD in being able to recognize symptoms and self-manage their symptoms. The increase in education has been shown to decrease anxiety with the disease and improve quality of life with IBD patients (Conley & Redeker, 2016). Patients and families suffering from IBD could benefit from an education program in this area.

Chapter II

Literature Review

A literature review over self-management education for patients with inflammatory bowel disease (IBD), which encompasses Crohn's disease and ulcerative colitis, is necessary to assess the effectiveness and need for patients in rural areas. The purpose of the study was to assess the current knowledge of IBD, self-management skills and resources for IBD for people suffering from the condition. The project also examined the effects of the education provided.

The review began looking at IBD, and the complications associated with it. The review discussed the significance of the education and support for IBD patients and examine current treatment and medications for controlling the condition for patients to attempt to have a good quality of life. The final discussion will involve the research studies that involve self-management and other education to attempt to improve patients' anxiety and other psychosocial issues as well as quality of life. The review will assist in showing the results of other education programs presented to IBD patients and their thoughts and feelings on the subject.

The literature review was performed using several search engines: CINHAL, PubMed, CDC, Summons, and Google Scholar. The key terms used to identify articles to

use in the literature review were inflammatory bowel disease, IBD treatment, IBD management, self-management, and inflammatory education.

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is an umbrella term for two different types of disease conditions, Crohn's disease and ulcerative colitis. The two conditions do not have a known cause. The research shows a combination of genetic and environmental factors to be involved but to what degree is not known. IBD involves the patient's own immune system attacking the gastrointestinal tract based on certain markers (Mayo Clinic, 2019).

The two disease conditions are similar in the fact that they both cause inflammation to the gastrointestinal tract. They do, however, have differences when it comes to what regions of the gastrointestinal tract are affected (Mayo Clinic, 2019). Crohn's disease causes inflammation and ulcerations anywhere throughout the GI tract, from mouth to anus and has more of a "cobble stone" or patchy appearance. Ulcerative colitis only causes inflammation in the colon and has a more continuous pattern with the inflammation (Mayo Clinic, 2019). Inflammation also differs in the different layers of tissues affected. Crohn's disease can affect multiple layers of tissue in the GI tract that can lead to fissures and other complications. Ulcerative colitis inflammation only affects the inner most lining of the GI wall (Mayo Clinic, 2019). The inflammation of the GI tract leads to similar signs and symptoms such as bloating, cramping, pain with stools, increased number of stools in a day, malabsorption of nutrients, diarrhea, and even blood in the stool, though more prominent in ulcerative colitis (Mayo Clinic, 2019).

The treatment for these two conditions is similar using medications and diets to avoid certain foods as well as manage symptoms. The medications usually involve anti-

inflammatory and immunosuppressive agents. Crohn's disease does not have a cure, and ulcerative colitis may only be cured with surgery and removal of the colon (National Institute of Diabetes and Digestive and Kidney Diseases, 2019).

Complications

Inflammatory bowel disease hospitalizations and costs have risen over the last few years. According to the CDC (2019), hospital admissions increased from 44.2 to 59.7 per 100,000 people and the average cost of ulcerative colitis admissions were $13,412, and the average cost of Crohn's was $11,345. Ulcerative colitis and Crohn's disease have their own specific complications; however, they share several main complications as well. The main complications that the two conditions share are colon cancer; skin, eye, and joint inflammation; medication side effects; primary sclerosing cholangitis; and blood clots (Mayo Clinic, 2019).

IBD increases a person's chance of colon cancer. General screening for this type of cancer usually occurs after a person turns 50 years old and calls for a colonoscopy every 10 years (Mayo Clinic, 2019). However, patients with IBD may need monitoring more frequently and sooner depending on patient age. The chronic inflammatory response from IBD may cause other symptoms for the patient, such as skin lesions, arthritis, and uveitis. The symptoms may worsen along with a flare up of the IBD. The chronic inflammation also places the patient at higher risk for blood clots and scarring of the bile ducts, which can lead to the primary sclerosing cholangitis (Rothfuss, Strange, & Herrlinger, 2006).

Physical symptoms, stereotypes of the disease and certain treatments may cause the people with IBD to suffer from psychosocial symptoms, on top of their physical

symptoms. The people who live with IBD may suffer from increased feelings of isolation, anxiety, and depression (McDonnell et al., 2014 , Lesnovska, Borjeson, Hjortswang, & Frisman, 2013). Patients with IBD need to have support or resources to assist in this area of their life as well. Lahat et al. (2014) found that 42% of the facilities did not have a clinical psychology service to support IBD patients. Treatment for IBD through the years has recognized that patients with this chronic condition need bio-psychosocial treatment as well as medical treatment (Todorovic, 2011).

The need for resources in IBD ranges throughout the entirety of the disease. Crohn's disease causes inflammation from the mouth to the anus. The inflammation can cause complications such as fistulas, abscesses, perforations, and fibrotic strictures (Lahat, Neuman, Eliakim, & Ben-Hoin, 2014). The patients may have uncontrolled urgency, some having up to twenty bowel movements in a 24-hour period (Anderson & Marsden, 2013). The people trying to manage this disease need assistance in improving their quality of life. McDonnel et al. (2014) explains how these patients can become depressed, unable to work and afraid to leave their homes due to their symptoms.

Symptoms of IBD require medical treatment/management to keep patients as healthy as possible as well as able to function and participate in everyday life. Symptom recognition, handling symptoms, planning life, and seeking new options were identified as some of the beneficial self-care techniques taught to IBD patients (Wickman et al., 2016). Symptom recognition was identified in two groups: physical and psychological sensations. The physical sensations varied from bloody diarrhea, constipation, abdominal distention, and pain. Psychosocial encompassed stress, loneliness, and symptoms of depression. Patients were asked to describe and keep track of their symptoms.

Recommendations from IBD Patients

Patients handling their symptoms involved tasks such as adapting the diet to their needs, using and obtaining medical treatment as needed and prescribed, as well as stress management and using alternative medicines when needed (Wickman et al., 2016). Changes in diet is a topic of interest of most IBD patients. The need to eat smaller, more frequent meals and avoiding certain foods can help a person keep symptoms at bay. Eating a healthier diet, cooking at home, and avoiding foods with a lot of preservatives can help reduce symptoms as well. Diets vary from person to person. Some expressed the need to avoid spicy foods when others do not; however, most people attempt to avoid dairy and see a difference in symptoms with the adjustment (Wickman et al., 2016).

Most patients also described the challenge in obtaining treatment from their gastroenterologists in a timely manner (Wickman et al., 2016). There are a limited number of specialists, making it difficult for people suffering from worsening symptoms to make an appointment and receive treatment without going to the emergency room. Some of the medical treatment involving enemas and suppositories were described as "challenging treatments" (Wickman et al., 2016). Patients often try alternative medicine and over-the-counter medication to assist with symptoms. Alternative forms of medicine involve heating pads, different spices, and even alcohol all to assist in pain and allowing the patients to fall asleep (Wickman et al., 2016).

Managing stress is attempted with physical activity. The informants described physical activity as an important factor in "feeling good" (Wickman et al., 2016). The activities ranged from biking to gym workouts. The exercise releases endorphins assisting patients in feeling less stressed and better about themselves (Wickman et al., 2016). Sleep

was also described as an important factor to monitor and obtain relief from stress. Patients often are up throughout the night with diarrhea, cramping, and pain. The lack of sleep can lead to elevated stress levels and worsening symptoms (Keefer, et al., 2012, Lesnovska, Borjeson, Hjortswang, & Frisman, 2013). The activities increased the patients' mental and physical well-being, which also improved psychosocial health. These activities were described as important for self-care (Wickman et al., 2016). Self-care is important for any patient. Some people had an easier time with these tasks than others. The degree of symptoms the patients were experiencing made it more difficult with worsened symptoms and easier if patients were not experiencing as many symptoms or had an absence of symptoms at that time.

The topics discussed above are topics that should not be taken lightly. Patients with IBD are suffering from physical and psychological symptoms. The physical and psychological symptoms need to be managed, and, with assistance, this could be achieved. The need of assistance from the health care team can assist patients meet and come up with management techniques, such as the ones discussed above.

Patients need resources to assist them in coping, self-managing, and improving their quality of life with their disease. Unfortunately, there is no one solution to solve all of the issues that these people go through. However, better life quality has been shown to be obtained with proper encouragement, skills, and planning (Plevinsky, Greenley, & Fishman, 2016).

Diagnosis and Treatment

The diagnosis of IBD is obtained through a detailed history and examination. The use of endoscopic procedures such as a colonoscopy or sigmoidoscopy allow for confirmation of IBD. The colonoscopy allows for examination of the entire colon while a sigmoidoscopy examines the rectum and the last part of the colon, the sigmoid (Mayo Clinic, 2019 & Crohn's and Colitis Foundation, 2019).

Treatment of the IBD does not revolve around curing the patient. The treatment goal for IBD is treating the inflammation and symptoms. Treating the underlying cause of IBD can solve many of the secondary issues that the patient may be facing, such as arthritis, and even help prevent further complications from developing. The treatment of inflammation can and should lead to the relief of symptoms and even lead to a patient being in remission (Mayo Clinic, 2019). Remission can be thought of as a period of lessened or no symptoms. However, there are different types of remission. The first type is considered clinical remission. This is where the patient is experiencing improved or no symptoms however, they could still have inflammation in the intestines. Endoscopic remission is when there is no inflammation seen in the intestines through act of a colonoscopy or other forms of endoscopy (Mayo Clinic, 2019).

The treatment of IBD usually begins with medications to treat inflammation. Anti-inflammatory medications range from corticosteroids to aminosalicylates such as mesalamine (Mayo Clinic, 2019 & Crohn's and Colitis Foundation, 2019). Medications act on certain parts of the bowel. The medication the patient is prescribed focuses on the primary source of inflammation for that specific patient. Patients with ulcerative colitis that suffer from more inflammation and bleeding around their anus and descending colon

would start with anti-inflammatory medications in the forms of enemas and suppositories to reach and best attack the area of inflammation (Crohn's and Colitis Foundation, 2019). However, patients may have multiple drugs that they are on depending on the level of symptoms. Patients can be on anti-inflammatory medications to help the inflammation and be on immunosuppressive medication to keep the patient from having more inflammation/damage.

The next type of medications used are immune system suppressors. These medications are used to suppress the patients' immune response. The medications work in a variety of ways to block or inhibit parts of the immune system that produces the inflammatory mediators causing the damage and inflammation to the gastrointestinal tract (Mayo Clinic, 2019). Some examples of these medications are methotrexate and mercaptopurine.

Another type of medication used to treat IBD are immune suppressants. Different forms of immune suppressants are available and called biologics or tumor necrosis factor (TNF)- alpha inhibitors. Medications of this variation work to neutralize a protein that is produced by the immune system suppressing the immune system's ability to work properly. Medications such as infliximab (Remicade), or adalimumab (Humira) are popular examples of this type of medication. The medications work systemically reducing the immune system to prevent damage and promote healing in many different disease processes including IBD (Mayo Clinic, 2019). The medication is given through subcutaneous injections. Subcutaneous injections involve injecting the medication with a small syringe or pen into the fatty tissue, such as upper legs, back of upper arms, or around the navel. The other ways of taking this type of medication are through oral pills

and infusions. Infusions involve the patient going to a facility and obtaining an intravenous line (IV) and infusing the medication directly into the vein.

Other medications are used in the treatment of IBD. The medications discussed above are used to control inflammation. However, there are more symptoms that patients may need help controlling while attempting to obtain remission. Physicians may promote certain over-the-counter medications to assist in controlling diarrhea, pain, and other symptoms. Medications to help control diarrhea symptoms are bulk-forming supplements, such as Metamucil, to assist with mild diarrhea, or an anti-diarrheal, such as Imodium, for more severe diarrhea (Mayo Clinic, 2019 & Crohn's and Colitis Foundation, 2019). Certain supplements may also be recommended or helpful to prevent further issues from developing with IBD. Patients who have or are at risk for osteoarthritis and anemia may be recommended to take iron, calcium, and vitamin D supplements (Mayo Clinic, 2019).

Inflammatory bowel disease often causes patients to suffer from lack of appetite or have pain and cramping when eating. Nutritional support and special restrictions in a person’s diet may be required if symptoms are severe enough. Avoiding certain foods can even assist in relief and avoid increasing symptoms (Mayo Clinic, 2019 & Crohn's and Colitis Foundation, 2019). Self-management skills can assist patients in monitoring their symptoms when eating and what foods could potentially worsen their symptoms (Crohn's and Colitis Foundation of America, 2014). Dairy products can increase gas and diarrhea, and many patients have found limiting dairy can assist in avoiding these symptoms. Avoiding high-fat foods may also assist in limiting symptoms. Crohn’s disease in the small intestine does not allow the person to absorb fats properly and can worsen diarrhea

and other symptoms (Mayo Clinic, 2019). Foods high in fiber, such as raw fruits and vegetables can also cause discomfort (National Institute of Diabetes and Digestive and Kidney Diseases, 2019). Other general rules with nutrition can be followed by avoiding spicy foods, alcohol, and caffeine. Not every person with IBD with will require the same exact diet; however, dairy products, nuts, and red meat are general food types to be careful with (Wickman et al., 2016).

Pain is another major symptom that can cause patients issues and affect their quality of life (CDC, 2019 & Conley & Redeker, 2016). Pain can be controlled with mild pain relievers such as Tylenol; however, pain medications involving non-steroidal anti-inflammatory drugs (NSAIDs) can actually worsen symptoms (Mayo Clinic, 2019 & Conley & Redeker, 2016). For this reason, it is important to discuss medications and symptom management with the health care team and have education on the medications and self-management skills to know what to avoid and what can help.

The last form of treatment for IBD often requires surgery. Surgery is the last option used to assist with symptoms due to it being the most invasive. The surgery treatment for Crohn's disease and ulcerative colitis differ in that one is more of a curative treatment and the other is more symptom relief. Ulcerative colitis can be "cured" most of the time with surgery. However, the surgery requires removing the entire colon and rectum, called a proctocolectomy (Mayo Clinic, 2019 & CDC, 2019). In this surgery, the small intestine is used to make a pouch and will then be re-attached directly to the anus. The surgery is done to eliminate the disease and allow the patient to expel waste normally, to a certain degree. If there are issues and the ability to make a pouch is not an option, an ileal stoma will be created which is an opening in the abdomen that will allow

the patient to expel waste into a bag (Mayo Clinic, 2019). The surgery, for the most part, relieves the patient of symptoms and "cures" the patient of ulcerative colitis.

The surgery for Crohn's disease is used for symptom relief. People with Crohn's disease often end up requiring at least one surgery in their lifetime. Some require more surgeries for symptom relief. The surgery removes portions of the bowel that are damaged and reconnects the healthy tissue. The surgery often relieves patients of their symptoms for some time. The issue with Crohn's disease is that inflammation and damage can re-occur in another area anywhere from mouth to anus, but usually re-occurs near the reconnected tissue. Surgery will also be done on those who develop fistulas or to drain an abscess, if one of those develops (Crohn's and Colitis Foundation of America, 2014 & Mayo Clinic, 2019).

Treatment for IBD can vary depending on the degree of illness and how compliant a person is with treatment and diet. The use of self-management education can benefit those in educating on symptoms and treatment purposes and help patients know how to manage their symptoms the best at home and when a health care team is needed.

Support for IBD Patents

Patients with IBD can find living with the disease causes psychosocial issues such as isolation, anxiety, and depression (McDonnell et al., 2014). Anxiety rates range anywhere from 25% to 50% in IBD patients (McDonnell et al., 2014). People with IBD need support from either family/friends, clinicians/healthcare staff or even through telephone and electronic communication. The support helps these people cope and can improve quality of life. The need for support for people with IBD is very apparent within the research. Developing and promoting self-management skills is an important aspect of

involving patients in their treatment and can improve their quality of life (Todorovic, 2014, Keefer, et al., 2012). McDonnell et al. (2014) defines self-management as "…the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition" (p. 34). Self- management is considered a more "holistic" approach to manage chronic conditions, such as inflammatory bowel disease, and can improve health-related quality of life (McDonnell et al., 2014).

Health-related quality of life, or HRQOL, is defined by the World Health Organization as a "state of complete physical, mental and social well-being and not merely the absence of disease" (as cited in McDonnell et al., 2014). This definition explains why patients with chronic conditions like IBD need support while dealing with this disease in their everyday life. Patients should not be expected to battle this alone. As nurses, there are ways to support our patients and improve their self-management skills while improving their HRQOL. Nurses must assist/support patients whenever we can, whether it be providing information, listening to their needs, or aiding them in their treatment, plan of care, or self-management programs.

Support has many different definitions. The Cambridge University Press (2019) defines *support as* "to help emotionally or in a practical way" and "to agree with and give encouragement to someone or something because you want him, her, or it to succeed." Support can be shown to patients by their own family/friends, clinical staff, and others with chronic conditions. Providing patient information and involving the patients in the decision making of their care is noted as being important in providing effective support for these patients to manage their disease (Glatter, Sephton, & Garrick, 2014). Patients

need different forms of support, such as social support, and resources/tools to aide them in their self-management of their condition, stress reduction and health-related quality of life.

Barriers

Self-management skills can benefit patients with IBD. No matter how helpful an intervention can be, there are always barriers or obstacles that can keep patients from obtaining the needed intervention. One of the barriers for a rural community is always access to care. Access to healthcare can be a challenge for some. Not all patients live close to health care facilities where they can easily make appointments, especially in rural areas where patients must drive, sometimes hours, to get to an appointment. The lack of specialists in an area can also play to the fact that patients may not be able to get into a specialist for months at a time, though treatment is needed. The Standards Group recommends minimizing the impact of a "flare up" on patients, their symptoms should be treated quickly (Anderson & Marsden, 2012). This can be an issue for some patients suffering from flares. Access can also be a barrier people will have to overcome to participate in self-management seminar. A solution to this could be to have specialists rotate to rural towns in certain areas to make less of a drive for patients.

Another barrier would be to have the right information and self-management skills to assist patient's quality of life. Barlow et al.'s (2010) review of self-management articles proved that education alone does not show a significant change in a patient's symptoms or quality of life. When education was partnered with self-management skills, the studies showed more symptom control and improvements in quality of life. Even

though barriers still exist for the self-management and education, the barriers can be overcome to assist in the benefits for patients suffering from IBD.

Summary

The literature on IBD shows how demanding the condition can be on a person. These people suffer from numerous physical symptoms, such as pain, cramping and diarrhea. The symptoms from their condition affect not only their body but their mind. People with IBD need support in any form they can obtain it, from family to healthcare, to others who have the same condition.

Treatments for IBD also vary in degree of disease with different types of medications, diet and lifestyle changes, as well as surgery as the last resort. Qualitative studies have shown that patients feel the need for more knowledge and skills to manage their condition (Lesnovska et al., 2013; Wickman et al., 2016). The self-management techniques and education can use these treatments to inform and teach patients how to self-manage their symptoms at home with lifestyle changes, monitoring symptoms and being compliant with medications, diets and explanations on why these things are important.

Patients with IBD need assistance and support just like patients with any other chronic disease and should have improved resources to instruct them on the education of their condition and self-management of the symptoms, medications and lifestyle changes. The research shows promise in self-management of the condition improving a patient's symptoms and overall quality of life. The proper resources can be put together and rotated to certain rural areas to assist in overcoming the condition of inflammatory bowel disease.

Chapter III

Methodology

The purpose of the study was to assess the current knowledge of inflammatory bowel disease, self-management skills, and resources for IBD in people suffering from the condition. This chapter outlines the design for this research project as well as the target population, instruments, and project procedures.

Project Design

A mixed methods design was chosen for this particular study. The study used a pre and post-test design on individuals with IBD. The design was chosen to assess the individuals' opinions and knowledge before and after an educational presentation about IBD, self-management skills, and resources. The individuals were invited to participate in the education presentation and participate in the study by answering a pre and post-test. The questionnaire and pre-test (Appendix A) was given before the education, and the post-test (Appendix C) was after receiving the education (Appendix B). The information obtained was used to assess the individuals' knowledge and self-management of IBD. The questionnaire also assessed the knowledge of resources in the area, as well as the individuals' opinions of this resource and others. The results of the study are used to work towards increasing the individuals' knowledge of their condition and assist in promoting more resources for areas in need.

Rural areas, such as the one in this study, lack the physicians and resources for patients suffering from chronic diseases, such as IBD (Benchimol et al., 2018). The study could potentially lead to more knowledgeable patients and a possible increase in resources in the area.

Sample/Target Population

The target population for this project was adults with IBD. The researcher recruited participants through social media, personally known adults with IBD, and support groups for adults with IBD. Participation in the project was voluntary, and participants were told they could stop participating at any time.

Inclusion and Exclusion Criteria

Inclusion criteria: participants were 18 years and older, able to read and understand English, and have a diagnosis of Crohn's disease or ulcerative colitis.

Exclusion criteria: individuals under the age of 18, not able to read and understand English or does not have a medical diagnosis of Crohn's disease or ulcerative colitis.

Data Collection

The participants were given the pre-survey (Appendix A) before the educational presentation (Appendix B) and the post-survey (Appendix C) after the presentation. The measurement tools used were pre and post surveys. Appendix A, B, and C were created by the author of the study. The author evaluated tools used in previous studies that were discussed in chapter two. Questions were used to obtain information about patients'

current knowledge of their condition, self-management skills, the current status of their IBD, support, and use or want/need of resources in the area the participants are from.

The surveys were administered online through an emailed link that contained the educational presentation and pre and post-tests. This design was chosen over a live presentation due to pandemic and social distancing to provide the greatest amount of safety to the participants. The participants had two weeks to listen to the presentation and complete the surveys. A convenience sampling of participants was utilized.

The purpose of this study was to evaluate the knowledge, self-management skills, and need for resources in the IBD population in the areas from which the participants are from. The study provided the participants with knowledge about IBD as well as self-management skills. The study also assess the participants' reaction to the educational session and inquired about the need for more resources such as this one.

Protection of Human Subjects

The approval from the researcher's scholarly project committee was obtained before collecting data. Permission was also obtained by the Institutional Review Board at Pittsburg State University. The author upheld the four basic principles of human subject protection including justice, respect for subjects, beneficence, and non-maleficence.

Participants were allowed to leave the study at any point in time if the participant felt the need. Participants were also educated that their responses to the surveys would not influence any advantage in their participation of a drawing to win a $25 gift card for participating in the study.

The Appendix A and Appendix C data were collected by the use of Qualtrics, survey software used to design, send, and analyze online surveys. Qualtrics does not

record IP or email addresses, so responses were kept confidential. The data was analyzed through using Microsoft Excel software. The emails were only used to communicate with the participants and were not shared. Only the author and the author's scholarly project advisor had access to the surveys. No personal identifiers were placed on the survey.

Analytical Methods

Descriptive statistics were used to describe the demographic data. The qualitative data from the survey was also evaluated. The qualitative information looked at how the patient felt their treatment is going at that point in time and allowed them to communicate difficulties they have had with IBD. Participants were also able to express their feelings and emotional distress that the condition and treatment has caused them.

Timeline

The participants were given Appendix A along with the education video, Appendix B and Appendix C. The participants had two weeks to watch the presentation and complete the surveys. The author provided this in the instructions with the pre- and post-test.

Strengths and Weaknesses

The strengths of the study involved the use of Appendix A and C. Appendix A acted as the controls for the study to evaluate the change, if any, to Appendix C after the educational intervention, Appendix B. Appendix A and C used the same participants to give clear evaluation of the intervention and assessment of the participants. Weaknesses of the study included a small sample size and human error. Human error is a possible weakness and involves relying on the participants answering the surveys honestly.

Summary

A mixed methods study design was used to assess patients before an educational presentation and after the presentation to assess patients' knowledge of IBD, self-management, support, emotional status and resource need. The information obtained from Appendix A and C was used to help identify the needs and views of the participants within this study.

Chapter IV

Evaluation of Results

The purpose of this study was to evaluate the knowledge, self-management skills, and need for resources in the IBD population in the areas from which the participants are from. The study provided the participants with knowledge about IBD as well as self-management skills. The study also assessed the participants' reaction to the educational session and inquired about the need for additional comparable educational resources. The questions asked within this study were the following:

1. Does the inflammatory bowel disease education improve participants' knowledge on symptom management?
2. Does inflammatory bowel disease education improve knowledge of self-management?
3. What are participants' knowledge levels with their medications for IBD?
4. What are the participants' demographics regarding ethnicity, age, gender, and rural vs. urban?
5. What is the participant's diagnosis (Crohn's or ulcerative colitis)?
6. What are some resources people with IBD would want?

Description of Population

The study had 143 participants over a two-week period that the study was held. The study specifically investigated the participants' demographics and will be discussed further on in the paper.

Analysis of Project Questions

Research Question One. Does the inflammatory bowel disease education improve participants' knowledge on symptom management?

The participants were asked to answer 12 questions before watching the educational presentation. The questions are located in Appendices A and C. The questions were used to assess the participants' knowledge before and after the presentation. Before the presentation 57.2% (n=83) answered question number 1 correctly, 42.1% (n=61) answered question 2 correctly, 31.7% (n=46) answered question 3 correctly, and 74.5% (n=108) people answered question 4 correctly. Questions 5 and 6 dealt with diet; 17.5% (n=25) answered question 5, and 34.3% (n=49) answered question 6 correctly. When participants were asked the type of doctor treated IBD, 76.4% (n=110) answered correctly. The number of participants that answered questions 8 and 9 correctly were 35.9% (n=51) and 92.9% (n=131). Questions 10 and 11 were true or false questions and had 68.5% and 78.5% of the participants answer correctly. The final question inquired about symptoms of IBD and had 25.9% (n=37) participants answer correctly.

The post-test used the same 12 questions to assess if the knowledge of the participants had changed after the presentation.

Likert scales were used to assess the participants' knowledge of certain aspects of their condition such as: medications, diet, managing symptoms, and stress management. When dealing with Likert scales the higher the number the more knowledge the person believes they have, Very Poor = 1 Poor= 2 Fair= 3 Good= 4 Very Good= 5. The knowledge of participants over their medications, management of symptoms, diet, and stress management were assessed. The participants rated their knowledge the highest at fair in all categories before watching the educational presentation, medication knowledge 49.7% (n=71), management of symptoms 41.3% (n=59), knowledge of diet 39% (n=55) and stress management 35.9% (n=52). The second largest number on the scale was the rating of 4 at 28% (n=40) for medication knowledge, 37.8% (n=54) for managing symptoms, 29.1% (n=41) for diet knowledge and 35.2% (n=51) for stress management. Knowledge of medications had 1.4% (n=2) ranking their knowledge poor and 13.3% (n=19) ranking their knowledge very good. Knowledge of managing symptoms had 0.7% (n=1) ranked at 1 and 7.7% (n=11) ranked at a 5. Knowledge on a healthy diet had 4.3% (n=60) their knowledge very poor and 10.6% (n=15) their knowledge very good. The ranking of both classifications of 4 (Good) and 5 (Very Good) increased in the post-test to 39.9% (n=57) and 9.8% (n=14). The Likert scales are presented and can be compared in Figures 1 and 2. Figure 1 represents the ranking of knowledge with symptom management during pre-test and Figure 2 represents the post-test ranking of knowledge with symptoms management. Knowledge of a diet was also ranked. The pre-test presented fair knowledge at 39% (n=55), shown in Figure 3 and 4 (Good) at 29.1% (n=41). The post-test presented fair knowledge at 43.8% (n=63) and good knowledge at 29.9% (n=43) shown in Figure 4.

Table 1

Number of Correct answers

Comparison of Pre and Post test			
Pre-Test	# Correct	Post Test	# Correct
1	83 (57.2%)	1	83 (57.2%)
2	61 (42.1%)	2	68 (47.6%)
3	46 (31.7%)	3	50 (35.2%)
4	108 (74.5%)	4	110 (79.1%)
5	50 (35%)	5	49 (34.8%)
6	49 (34.3%)	6	51 (36.2%)
7	110 (76.4%)	7	94 (67.1%)
8	51 (35.9%)	8	59 (41.8%)
9	131 (92.9%)	9	127 (90.7%)
10	98 (68.5%)	10	104 (73.8%)
11	113 (78.5%)	11	122 (86.5%)
12	37 (25.9%)	12	32 (22.4%)

Figure 1.

Current Knowledge on Management Pre-test

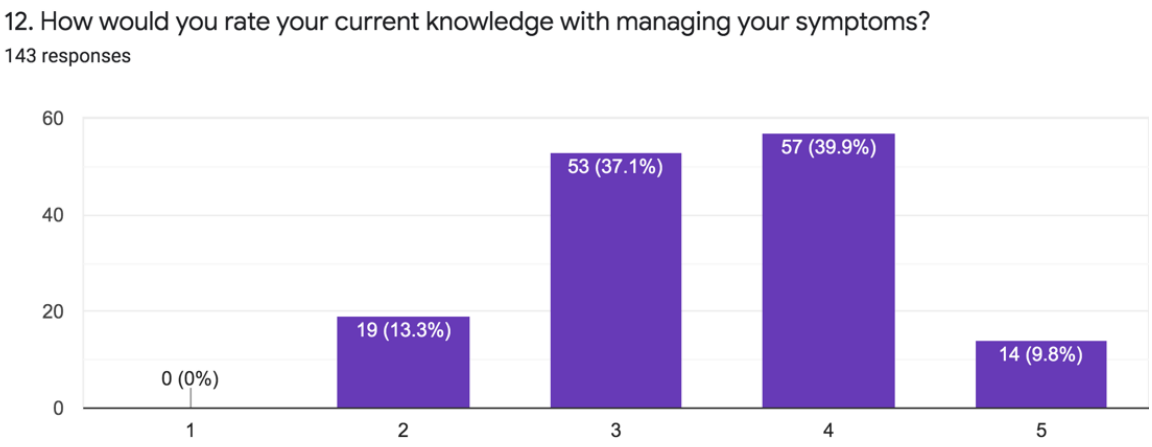


Figure 2.

Current Knowledge on Management Post-test

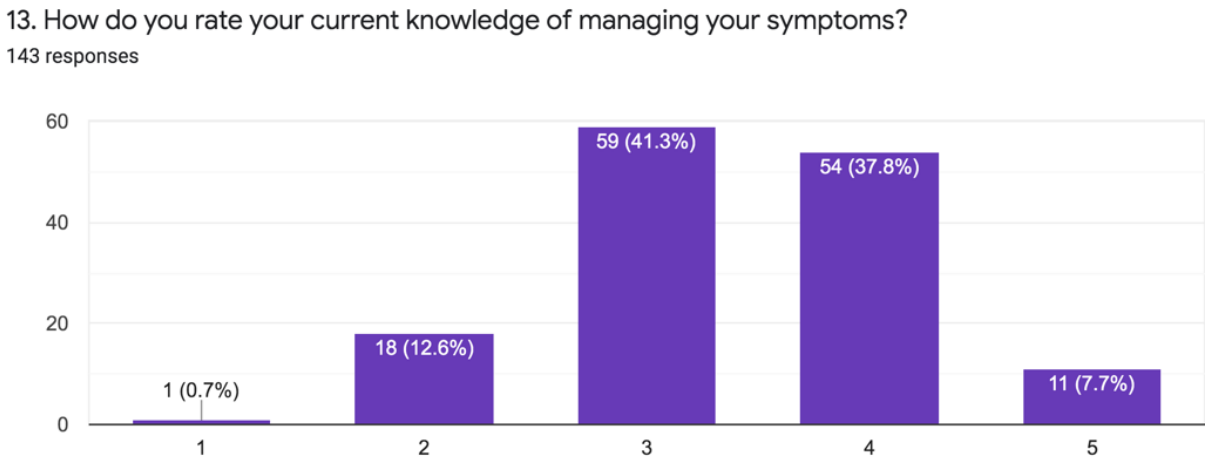


Figure 3.

Knowledge of Healthy Diet Pre-test

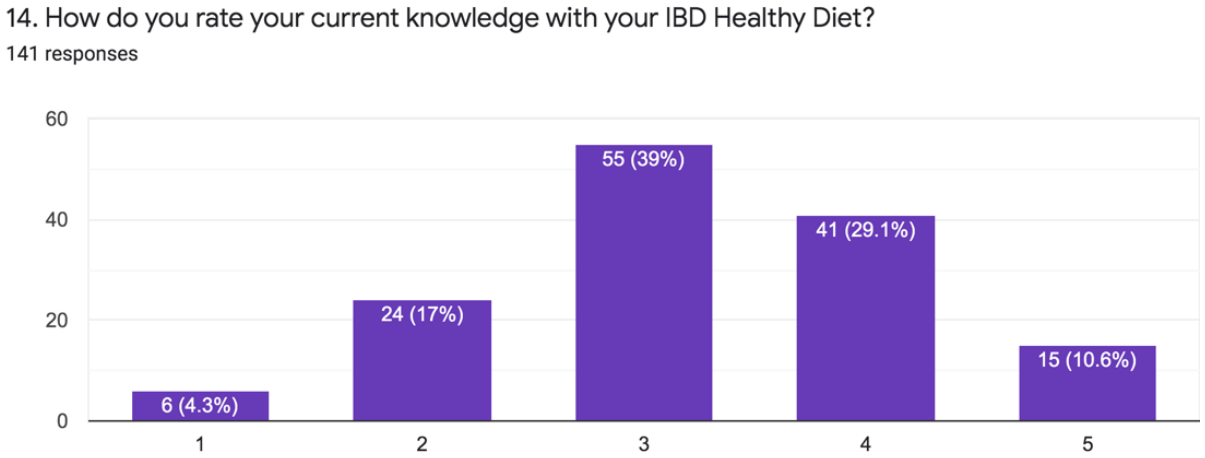
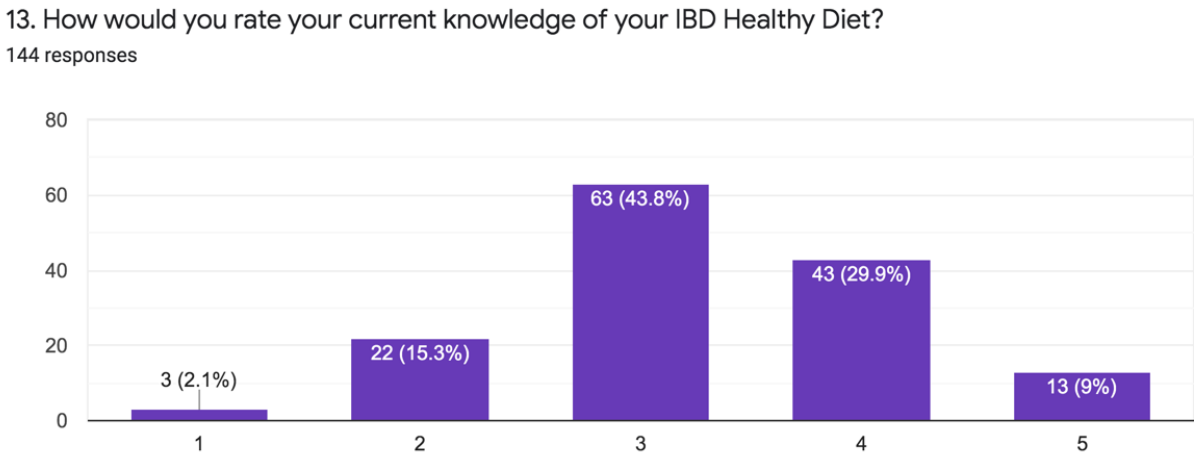


Figure 4.

Knowledge of Healthy Diet Post-test



Research Question Two. Does inflammatory bowel disease education improve knowledge of self-management?

The research project involved assessing and educating people with the diagnosis of inflammatory bowel disease. The pre- and post-test evaluated the participants' knowledge of foods to avoid, foods that are more beneficial, and things that could cause a flare up of IBD, such as stress. The educational video gave facts and the answers to the pre- and post-test. The educational video was made to be a resource to provide knowledge that could improve self-management. The post-test was used to see if the knowledge was obtained after seeing the educational video.

Table 1 above shows a comparison of the pre- and post-tests. As discussed in the previous section, the results slightly improved with the post test. Questions 13, 14 and 15

dealt with management of IBD. As stated previously, the knowledge level of health diet, symptom management and stress management were all rated on a Likert scale. Knowledge of managing symptoms had 0.7% (n=1) as very poor and 7.7% (n=11) at very good. Knowledge on a healthy diet had 4.3% (n=6) rate their knowledge as poor and 10.6% (n=15) rate their knowledge very good.

Participants were also asked what type of diet, if any, that they used to manage their symptoms. The most common responses were eating a "healthy, bland diet." Many responses involved avoiding food that caused irritation or flares, such as low fat, low residue, and minimal or lactose-free diets. Other responses included no raw fruit or vegetables, low refined sugar, red meat, nuts, and spicy foods. The more uncommon responses focused on vegan and vegetarianism and gluten free diets.

The pre- and post-tests had questions 5 and 6 that involved asking about proper foods to eat and foods to avoid when diagnosed with IBD. Question 5 asked participants what foods should be avoided in IBD in multiple choice format. The correct choice was steak, broccoli, and cauliflower. Fifty participants (35%) answered correctly on the pre-test, and forty-nine participants (34.8%), answered correctly on the post-test.

Question 6 asked, in multiple choice format, what foods were good to eat with IBD. The correct answer was chicken, blueberries and squash. Forty-five participants answered correctly in the pretest. and fifty-one participants, (36.8%), answered correctly on the post-test.

Research Question Three. What are participants' knowledge levels with their medications for IBD?

The study also looked at participants' knowledge and comfort with medications for IBD. The pre and post-test used Likert Scale on Question 12 to rate the participants' knowledge of their medications before and after the educational video. The graph shown in figure 1 below shows us the rating of knowledge based on Very Poor = 1 Poor= 2 Fair= 3 Good= 4 Very Good= 5. Almost one-half (49.7%) of the participants rated their knowledge as a 3, Fair, in both tests.

Figure 5.

Current Medication Knowledge Pre-test

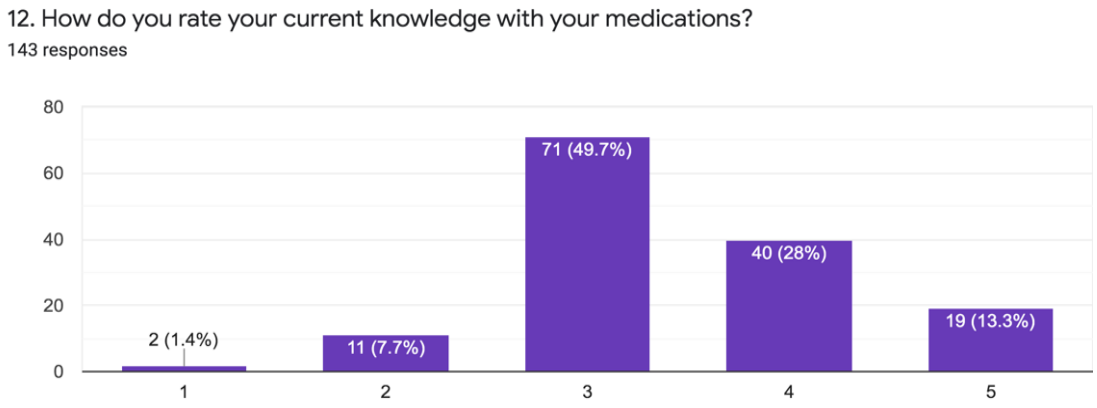
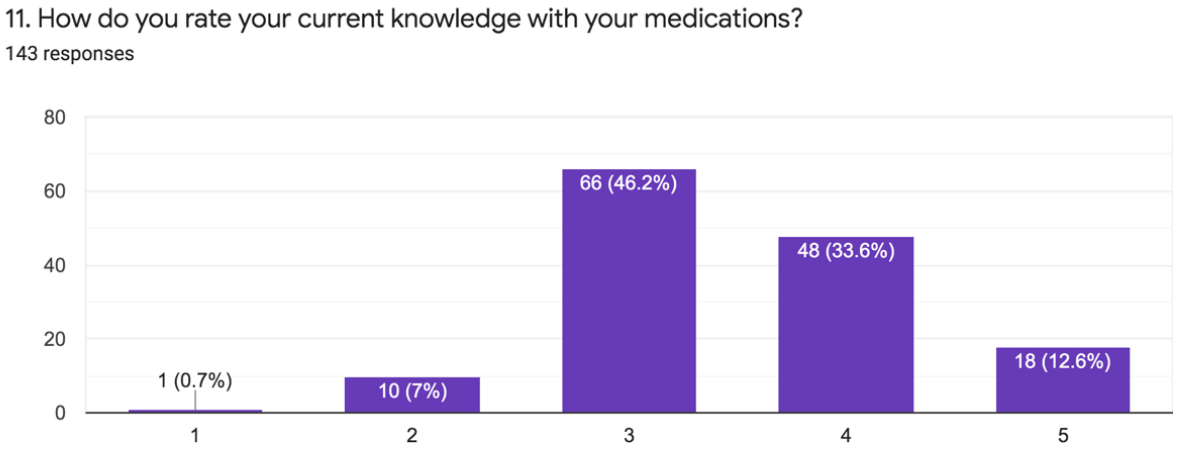


Figure 6

Current Medication Knowledge Post-test



However, the post-test percentage for the number for good increased from 28% to 33.6% in the post-test. The number 5 rating very good was 13.6% pre and 12.6% post. Eleven of the participants (7.7%) rated their knowledge of medications at poor, and post-test the number dropped to ten participants or 7%.

Question 8 asked a multiple-choice question of which medication to avoid with a diagnosis of IBD. The correct answer to the question was aspirin. Fifty-five participants answered correctly, 35.9%, on the pre-test and 41.8% answered correctly on the post-test. Figures A and B depict the percentages of the available choices in a pie chart.

Figure A .

Answers to Question #8 Pre-test

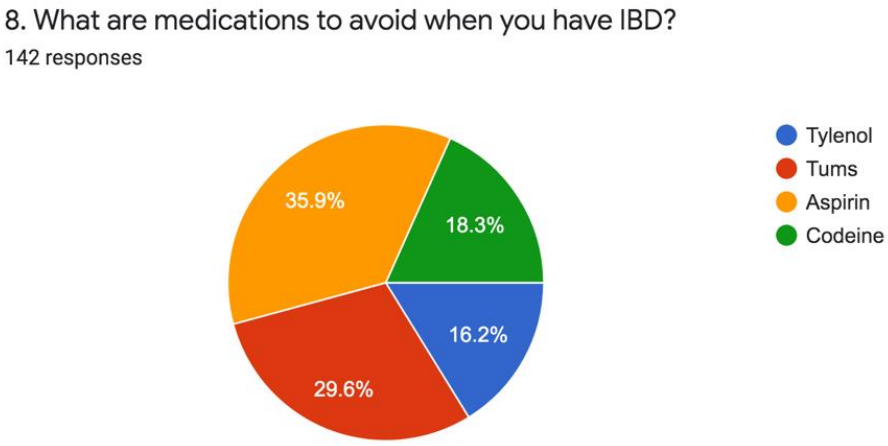
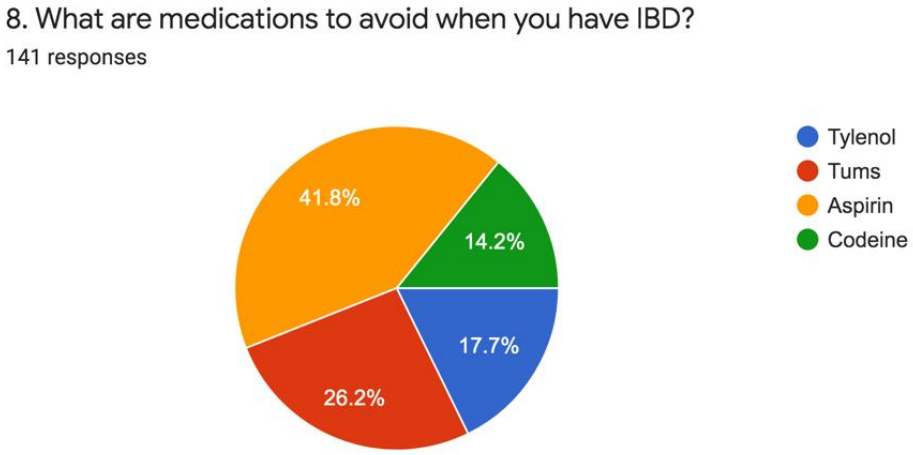


Figure B.

Answers to Question #8 Post-test



Research Question Four. What are the participants' demographics regarding ethnicity, age, gender, and rural vs. urban?

The age ranges of the participants in the study were 45.8% 30 to 49 years of age, 43.1% 18 to 29 years of age, 10.4% 50-69 years of age and 0.7% 70 + years of age. The breakdown of age range can be seen in Figure C. The gender was 49.7% male and 50.3% female shown in Figure D. The study consisted of 82.1% white/Caucasian, 7.6% African American, 4.8% Asian, 3.4% American Indian or Alaskan Native, 2.1% Native Hawaiian or Pacific Islander, which can be seen in the pie chart in Figure E.

Another variable that was assessed within the study was if the participants lived in a rural or urban setting. The definition for rural areas was that the area comprise of open country and settlements with fewer than 2,500 residents. The definition for urban was an area that has greater than 2,000 residents and are densely settled areas. The majority lived in urban areas with 80.6% and 19.4% in rural areas. Figure F depicts the ratio of rural versus urban.

Figure C.

Age Range

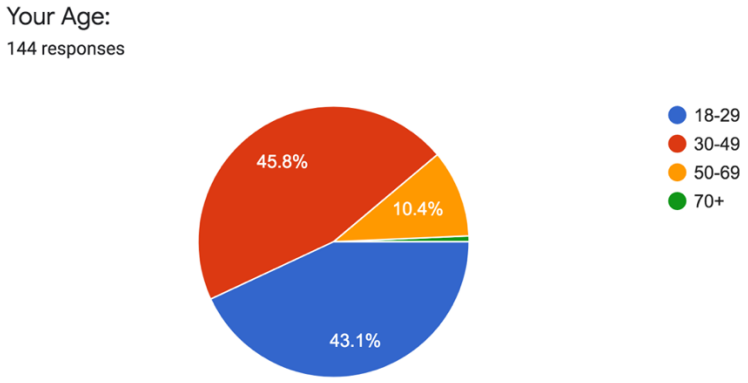


Figure D.

Gender Percentage.

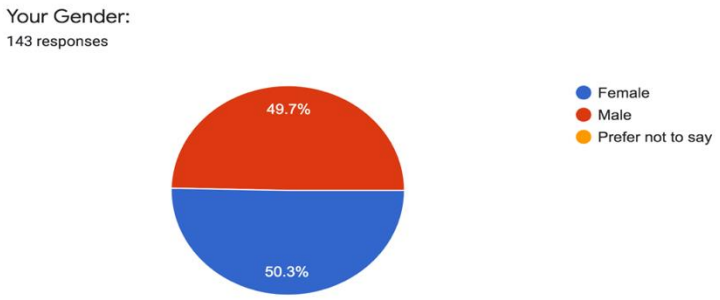


Figure E.

Diversity of Participants

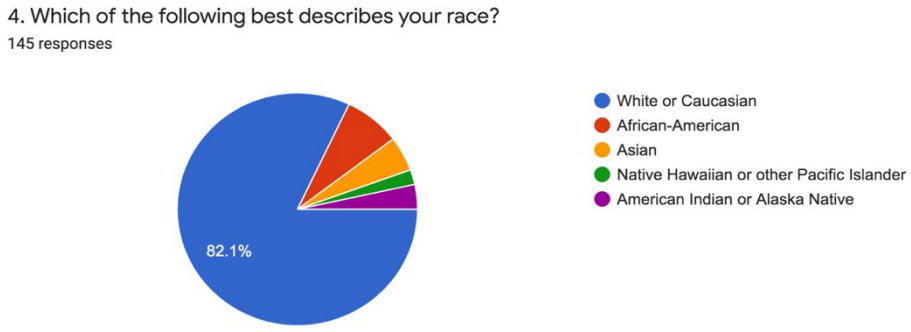
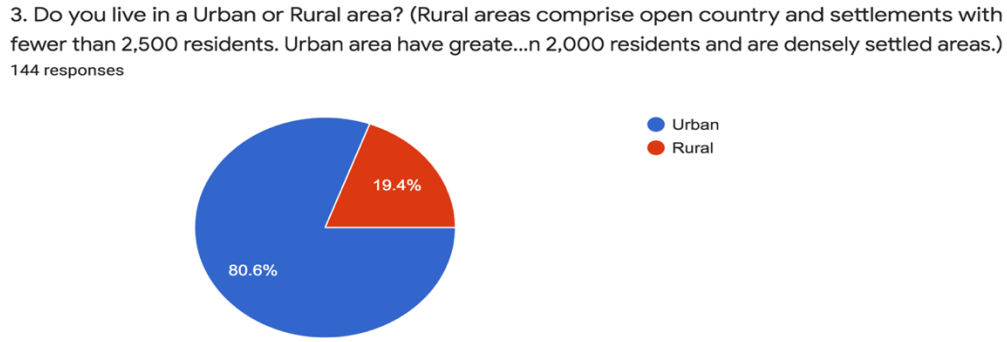


Figure F.

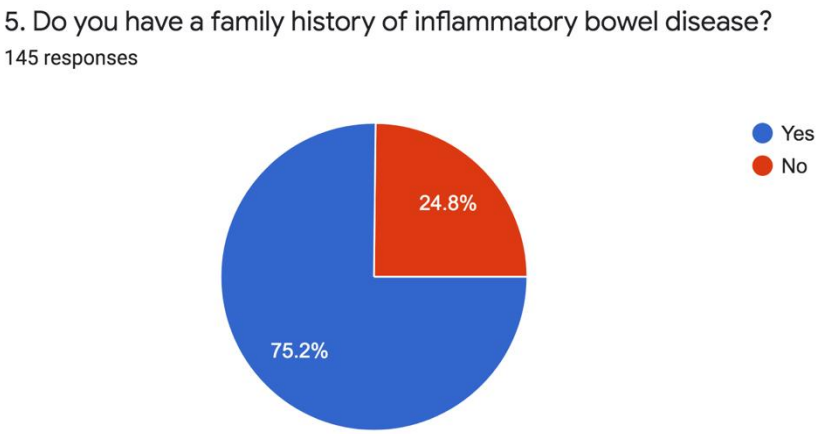
Urban vs. Rural Participants



Family history of inflammatory bowel disease, the type of IBD and symptom control were also variables used within the study. 75.2% of the participants had a family history of IBD and 24.8% did not. Figure G is a visual representation of this difference.

Figure G.

Participant's Family History



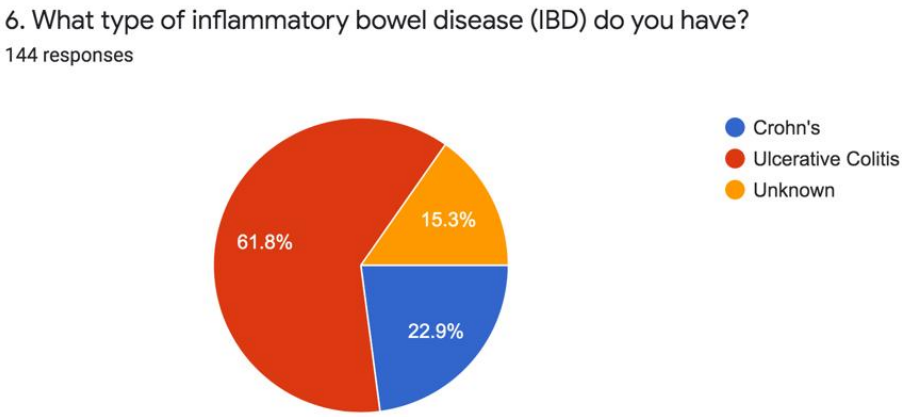
Research Question Five. What is the participant's diagnosis (Crohn's or Ulcerative Colitis)?

Inflammatory bowel disease is an autoimmune disease of the digestive system. The differences in Crohn's disease and ulcerative colitis has been discussed . One of the research questions asked for this study was to determine the ratio of Crohn's and Ulcerative colitis. Ulcerative colitis was reported the primary diagnosis in 61.8% of the participants. The percentage with Crohn's disease was 22.9%. Lastly, 15.3% of the participants did not know if they had Crohn's disease or ulcerative colitis. When asked if

the participants felt their symptoms were controlled 80.1% answered yes. Figure 1C does a visual break down of the percentiles for each category.

Figure H.

Participant's Diagnosis



Research Question Six. What are some resources people with IBD would want?

The participants were asked if the participants felt there were enough resources around for them to use. 73.4% of the participants answered yes.

Participants were asked: If you could choose a resource to have, what would it be? Multiple answers were obtained. Participants requested resources such as contact line to call when a person has questions about their condition or if they need to go to the hospital, and applications to keep track diet, medications, and symptoms. Other resource requests were online consulting, good healthy recipes, affordable dieticians and psychologists to contact.

Diet is another important variable that the study assessed along with support systems. 53.5% of the participants marked that they followed a certain diet and 46.5%

answered that they did not follow a specific diet. When asked to specify which diet that the participants who answered yes followed, they said they follow a certain diet, the most common answers were “healthy diet”, “bland diet”, “small portions”, and “low dairy”. Support can be a major factor in the treatment of IBD.

Participants were also asked if they felt that they had a good support system. Support is important with any illness, 87.3% of the participants reported that they felt that they did have enough support. The participants were also given open ended questions to gather further data on what they would like to know more about. The most common comments involved diet, exercise, cause of IBD, medications, and treatments. The other comments involved the pathophysiology of the disease, how to prevent IBD, and efficiency of treatments.

Summary

All project questions were addressed by the study. The study showed that the participants’ felt that their knowledge of their diet, medications, and management of IBD improved slightly in the Likert scales. The data also presented demographics on the participant proving the study had good diversity in sex, race, disease process and environment. The data also supplied examples of the types of resources the participants would want such as contact lines for IBD questions and applications to help manage and monitor their symptoms and diet. The data aligns with what this study set out to find. The data can be used to further assist in getting wanted resources and education to people with IBD.

Chapter V

Discussion

Relationship of Outcomes to Research

The purpose of this study was to evaluate the knowledge, self-management skills, and need for resources in the IBD population in the areas from which the participants reside. The data was collected by pre-test/survey and post-test/survey. The participants were given a two week period to complete the pre-test/survey, educational video, and post-test/survey. The data was then used to answer the research questions.

The first question was "Does the inflammatory bowel disease education improve participants' knowledge on symptom management?" Education in IBD and self-management skills has shown to assist patients in being able to recognize symptoms and self-manage their care at home. The increase in education has been shown to decrease anxiety with the disease and improve quality of life with patients (Conley & Redeker, 2016).

The results of this study have evidence that would support this claim. Questions 2,3,4,6,8,10 and 11 all had increased correct answers from the pre-test to the post-test, shown in Table 1 in chapter 4. A Likert scale was used on Question 12 to rate the participants' knowledge of their medications before and after the educational video. The rating of knowledge was based on Very Poor = 1 Poor= 2 Fair= 3 Good= 4 Very

Good= 5. Knowledge was shown to be gained by the post-test knowledge on medication increasing percentage of number of rating Good knowledge, from 28% to 33.6%. Knowledge of managing symptoms had 0.7% (n=1) ranked at 1 and 7.7% (n=11) ranked at a 5. Knowledge on a healthy diet had 4.3% (n=60) their knowledge at a 1 and 10.6% (n=15) their knowledge at a 5. The ranking of both classifications of 4 (Good) and 5 (Very Good) increased in the post-test to 39.9% (n=57) and 9.8% (n=14). The Likert scales are presented in the previous chapter and can be compared in Figures A and B. Figure A represents the ranking of knowledge with symptom management during pre-test, and Figure B represents the post-test ranking of knowledge with symptoms management. Knowledge of a diet was also ranked. The pre-test presented knowledge at fair at 39% (n=55), shown in Figure C, and good at 29.1% (n=41). The post-test presented fair at 43.8% (n=63) and good at 29.9% (n=43) shown previously in Figure D. The increase in correct answers on the post-test and increased knowledge give evidence to the educational resource improves the knowledge on symptom management.

The second research question was “Does inflammatory bowel disease education improve knowledge of self-management?”. Providing patient information and involving the patients in the decision making of their care is noted as being important in providing effective support for these patients to manage their disease (Glatter, Sephton, & Garrick, 2014). As discussed in a previous section, the education provided to the participants dealt with information over management of IBD and to increase the participants’ ability to self-manage by giving them the information required to do so. The pre and post-tests did not have a specific question to grade self-management. However, as discussed, the knowledge levels on the categories discussed in the study increased. The data obtained

supports previous studies in the fact that people want information. The study cannot conclude that the information helped the participants improve their self-management skills, but it did assess their knowledge on the topics needed to self-manage their IBD with the pre and post-test.

The third question was “What are participants’ knowledge levels with their medications for IBD?”. Providing patient information and involving the patients in the decision making of their care is noted as being important in providing effective support for these patients to manage their disease (Glatter et al., 2014). The different forms of support, such as social support, and resources/tools have been shown to aide people with chronic conditions. The study collected knowledge on the medications that they are taking to treat their IBD. The study did show improvement in the knowledge of their medications with this education resource providing support to supply people with chronic conditions support, such as education/information to improve their overall knowledge base of their condition.

The fourth question was “What are the participants’ demographics regarding ethnicity, age, gender, and rural vs. urban?”. The study was used to assess demographics of IBD. The CDC estimated around 3.1 million United States adults were diagnosed with IBD in 2015 (Dahlhamer et. al, 2016). In 1999, the estimated number of United States adults with inflammatory bowel disease was 1.8 million. The rate of IBD is growing. Demographics can help assess what populations are at risk and assist in prevention. The majority of the participants age ranges in the study were 30 to 49 years of age (45.8%), and 18 to 29 years of age 43.1%. The gender was almost split 50/50 with 49.7% male and 50.3% female. The study found that the majority of the participants were of

white/Caucasian (82.1%), and the next closest ethnicity was 7.6% African American. The study could show that IBD may be more prevalent in Caucasians than other ethnicities.

The fifth research question was “What is the participant’s diagnosis (Crohn’s or ulcerative colitis)?”. The Crohn’s and Ulcerative Colitis Foundation of America in 2014 found that "the total number of new cases of Crohn's disease diagnosed each year was 10.7 per 100,000 people, or approximately 33,000 new cases per year. The total number of new cases of ulcerative colitis diagnosed each year was 12.2 per 100,000 people, or approximately 38,000 new cases per year” (Crohn's and Colitis Foundation, 2019). The data that was collected in this study showed that ulcerative colitis was reported the primary diagnosis in 61.8% of the participants. The percentage with Crohn’s disease was 22.9%. The recent study dose support that ulcerative colitis is more prevalent than Crohn’s disease.

The sixth and final question was What are some resources people with IBD would want? The Standards Group recommends minimizing the impact of a “flare up” on patients, to do this their symptoms should be treated quickly (Anderson & Marsden, 2012). Access to care and information has been discussed throughout this study. Patients handling their symptoms involved tasks such as adapting the diet to their needs, using and obtaining medical treatment as needed and prescribed, as well as stress management and using alternative medicines when needed (Wickman et al., 2016). Research has shown that patient who can self-manage symptoms have better prognosis and that a great deal of concern from patients comes from issues with access to care (Wickman et al., 2016). The answers collected from this question in the study provide support to this research. Participants requested resources such as contact line to call when a person has

questions about their condition or if they need to go to the hospital, and applications to keep track of diet, medications, and symptoms. Other resource requests were online consulting, good healthy recipes, affordable dieticians and psychologists to contact. All of the resources requested dealt with some form of quick access to care or a way to help them self-manage.

Observations

This study was a unique one due to the fact that it looked at not only demographics, but knowledge and it had a qualitative aspect to the study as well. The study did get a good look at knowledge for IBD and received much more feedback than predicted. The knowledge base in the data obtained was found to be higher than predicted. The participants also reported that they had a grasp of the basic knowledge but wanted more in-depth knowledge over certain topics, such as diet, exercise and medications.

The surveys/tests as well as the educational video received good feedback, and many thought it was a great introduction to IBD. However, a set a grading scale for the pre- and post-test and therefore lack some data that would help support the increase in knowledge obtained in the study. The lack of this was mainly due to time and the way the data was obtained made it difficult to sort through and grade individual tests.

The results obtained were positive. The study found that people with IBD had a general knowledge base but wanted help with more specific knowledge. Another observation included the number of participants in the study. The study involved more participants than predicted. The study also missed an opportunity to assess the reason for certain participants to have an unknown diagnosis. The results were hindered due to not

having control over the area in which the results were obtained. The goal was a rural population and instead had a more urban population in the study. The study was reassuring that people with IBD are willing to participate in studies like this to help better themselves and others. Many participants were willing to help and support one another.

Evaluation of Theoretical Framework

The theoretical framework chosen for this study was Orem's Self-Care Deficit theory. Orem's Self-Care Deficit Theory contains three interrelated theories: the theory of self-care, the self-care deficit theory, and the theory of nursing systems. The theory of self-care focuses on the ability of individuals to perform activities to maintain their health and well-being. The activities are called self-care requisites and focus on processes of functioning in everyday life, such as having sufficient intake, balanced activity with rest, and adequate socialization (Gonzalo, 2014). The self-care deficit focuses on when nursing is needed to assist the individual in maintaining or improving self-care.

The framework was used throughout the study in making an education resource to support people with IBD to help them self-manage their symptoms. The data collected supported the framework by showing the importance of knowledge to the people with IBD. The study described the knowledge levels of the participants before and after using the resource and also obtained what resources participants felt would help them manage their chronic condition. The project supported the use of nurse agency to help self-care demand by showing the improvement in the knowledge after the nurse agency (the educational intervention).

The one aspect that the study did not and could not measure was the use of the knowledge and actual improvement of management of symptoms. The study would have

required two parts and more time to go back and ask participants how the education has been used to improve their self-management of their symptoms. The recommendation is that this topic be examined further in future research studies.

Evaluation of Logic Model

The data obtained from the study supports the logic module that was made and presented in Chapter 1 of the study. The model visualized the organization of the project from the antecedents of the education program to the outcomes and lists the different types of examples. The antecedents contain the patients' demographics and baseline knowledge of their condition. The diagram begins at the left looking at the available resources received at the education program. The end of the diagram shows the outcomes. The outcomes included an increase in knowledge in areas that help people self-manage their symptoms. The study followed the logic model and showed improved knowledge with the model of the study.

Limitations

The study did have some limitations. The sample size of 146 participants varied from question to question on the pre- and post-test making it difficult to score the actual percentages of some of the questions. Some of the participants did not answer some of the questions or answered inappropriate answers or in another language that could not be read and used in the study.

The study looked at rural versus urban but due to being an online study the study could not examine one certain area for needs. The study originally was to evaluate a rural town but due to the pandemic, had to be done online. The study was held over a two-

week period, limiting participants and limiting the ability to assess improvement in self-management skills/knowledge and improvement in symptoms.

The study could not evaluate improved self-management of symptoms due to being online and due to time restraints; therefore, the evaluation of knowledge was used, along with participants' qualitative data to assess improvement with the educational resource and needs of the participants.

Implications for Future Projects and/or Research

The project could be carried out with more participants and in a better randomized fashion to increase the generalizability of the study. Changing the project to include a longer time frame and more in-depth education could improve the knowledge base that is needed. Extending the time period could also allow for the assessment of improved self-management knowledge on actual use and management of symptoms.

The incidence of IBD is growing in the U.S. and more studies need to be done to assist with the self-management of IBD. Many studies focus only on medication management and treatment. The studies could expand on self-management and dig further into following participants over long periods of time to evaluate what resources and self-management skills truly help these people who suffer from IBD.

Implication for Practice/Health Policy/Education

The recent data collected has given a small insight into education and self-management for people suffering IBD. If the study has done anything, it has shown that people with IBD want help and are willing to help find answers to better manage IBD. The data cannot change any policy or treatment at this time. The data obtained can be used to spark more studies on this topic.

Inflammatory bowel disease is a growing chronic condition that can cost the patient and health care a lot of money. Further research into self-management and the overall treatment of the patients need to be done to help determine what practices can benefit these patients by keeping them healthy and out of health care facilities. So much is still unknown about IBD and the treatment; if research can help provide people and their providers with more management practices, the better the outcomes for those with IBD.

Conclusion

The study was undertaken to evaluate the knowledge, self-management skills, and need for resources in the IBD population in the areas from which the participants reside. The data was collected by pre-test/survey and post-test/survey. The study demonstrated that people with IBD are willing to learn more and participate in studies and that knowledge was increased with the educational resource. Another important finding was that the participants want to learn more and want resources to help them learn more about and help them manage their inflammatory bowel disease. The information gained from the study will be beneficial to help guide future research and educational resources for people with IBD. The importance of this type of knowledge and resources for people with IBD is becoming more important with the increasing diagnosis of IBD. Practitioners and people suffering from the condition need to have the knowledge to help self-manage their symptoms and improve their outcomes.

References

American College of Gastroenterology. (2019). *What is a gastroenterologist*. Retrieved from American College of Gastroenterology: https://gi.org/patients/gi-health-and-disease/what-is-a-gastroenterologist/

Anderson, G., & Marsden, E. (2013, August 16). *Audit of an inflammatory bowel disease (IBD) telephone helpline set up and managed by IBD specialist nurses.* Retrieved from MAG Online Library: https://www.magonlinelibrary.com/doi/epub/10.12968/gasn.2012.10.5.24

Barlow, C., Cooke, D., Mulligan, K., Beck, E., & Newmann, S. (2010). A critical review of self-management and educatior interventions in inflammatory bowel disease. *Database of Abstracts of Review of Effects*, 11-18.

Benchimol, E. I., Kuenzig, M. E., Bernstein, C. N., Nguyen, G. C., Guttmann, A., Jones, j. L., . . . S. (2018). Ruraland urban disparities in the care of canadian patients with inflammatory bowel disease: population-based study. *Clinical Epidmiology,* 1613-1626.

Cambridge University Press. (2019). *Support*. Retrieved from Cambridge Dictionary: https://dictionary.cambridge.org/us/dictionary/english/support

Centers for Disease Control and Prevention. (2019, March 21). *Inflammatroy bowel disease*. Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/ibd/data-statistics.htm

Conley, S., & Redeker, N. (2016). A systematic review of self-managment interventions for inflammatory bowel disease. *Journal of Nursing Scholarship,* 118-127.

Crohn's and Colitis Foundation. (2019). *Mid-america chapter*. Retrieved from Crohns and colitis foundation: https://www.crohnscolitisfoundation.org/chapters/midamerica

Crohn's and Colitis Foundation of America. (2014, November). *The Facts about Inflammatory Bowel Disease.* Retrieved from Crohn's and Colitis Foundation of America: https://www.crohnscolitisfoundation.org/sites/default/files/2019-02/Updated%20IBD%20Factbook.pdf

Dahlhamer, J. M., Zammitti, E. P., Ward, B. W., Wheaton, A. G., & Croft, J. B. (2016, October 28). *Prevalence of inflammatory bowel disease among adults aged > 18 years- united states, 2015*. Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/mmwr/volumes/65/wr/mm6542a3.htm

Glatter, J., Sephton, M., & Garrick, V. (2014). The revised inflammatory bowel disease standards and the IBD nurse role. *Gastrointestinal Nursing*, 28-34.

Gonzalo, A. (2014, August 12). *Dorthea Orem: self-care deficit theory*. Retrieved from Nurseslabs: https://nurseslabs.com/dorothea-orems-self-care-theory/

Keefer, L., Kiebles, J. L., Martinovich, Z., Cohen, E., Van Denburg, A., & Barrett, T. (2012). Behavioral interventions may prolong remission in patients with inflammatory bowel disease. *HHS Author manuscript*, 145-150.

Lesnovska, K. P., Borjeson, S., Hjortswang, H., & Frisman, G. H. (2013). What do patients need to know? Living with inflammatory bowel diases. *Journal of Clinical Nursing*, 1718-1725.

Mayo Clinic. (2019). *Inflammatory bowel disease*. Retrieved from Mayo Clinic: https://www.mayoclinic.org/diseases-conditions/inflammatory-bowel-disease/symptoms-causes/syc-20353315

Mcdermott, E., Healy, G., Mullen, G., Keegan, D., Byrne, K., Guerandel, A., . . . Mulcahy, H. (2018, April). *Patient education in inflammatory bowel disease: a patient-centered, mixed methodology study*. Retrieved from Oxford Academic Journal of crohn's and colitis: https://academic.oup.com/ecco-jcc/article/12/4/419/4773946

McDonnell, E., Forry, M., O'Raghallaigh, J. W., Kelly, O., Patchett, S., & Ruane, A. (2014). Pilot study of a multitiered psychosocial support framework for inflammatory bowel disease patients. *Gastrointestinal Nursing Vol. 12, No. 3*.

National Institute of Diabetes and Digestive and Kidney Diseases. (2019). *Your digestive system and how it works*. Retrieved from National institute of diabetes and digestive and kidney disease: https://www.niddk.nih.gov/health-information/digestive-diseases/digestive-system-how-it-works

Plevinsky, J. M., Greenley, R. N., & Fishman, L. N. (2016). Self-manage in patient with inflammatory bowel disease: strategies, outcomes and integration into clinical care. *Clinical and experimental Gastroenterology*, 259-267.

Rothfuss, K. S., Strange, E. F., & Herrlinger, K. R. (2006). Extraintestinal manifestations and complications in inflammatory bowel disease. *World Journal of Gastroenterology*, 4819-4831.

Saibil, F., Lai, E., Hayward, A., Yip, J., & Gilbert, C. (2008). Self-management for people with inflammatory bowel disease. *Can J Gastroenerol* , 281-287.

Todorovic, V. (2014). Holistic support for IBD patients. *Independent Nurse Vol. 2013, No. 2*.

Wickman, U. L., Yngman-Uhlin, P., Hjortswang, H., Riegel, B., Stjernman, H., & Frisman, G. H. (2016). Self-Care patients with inflammatory bowel disease. *Gastroenterology Nursing*, 121-128.

APPENDIX

Appendix A

Pre-test

Creating a New Education Resource for Patients with Inflammatory Bowel Disease

NOTICE: If at any point in the study you feel you need to drop out, you may. Your answers do not influence your chances in the drawing.

For the following questions, please circle the letter by the answer that best represents you (one per item)

Demographics

1. Age
    a) 18-29
    b) 30-49
    c) 50-69
    d) 70+

2. Gender
    a) Male
    b) Female

3. Do you live in an Urban or Rural area?
   (Rural areas comprise open country and settlements with fewer than 2,500 residents. Urban areas have greater than 2,000 residents and are densely settled areas.)
    a) Urban
    b) Rural

4. Which of the following best describes your race?
    a) White or Caucasian
    b) Black or African-American
    c) Asian
    d) Native Hawaiian or other Pacific Islander
    e) American Indian or Alaska Native
    f) Other _____

5. Do you have a family history of inflammatory bowel disease?
    a) Yes
    b) No

6. What type of IBD do you have?
    a) Crohns
    b) Ulcerative Colitis
    c) Unknown

7. Do you feel your symptoms are currently controlled?
    a) Yes
    b) No

8. Do you have access to a gastroenterologist?
    a) Yes
    b) No

9. Do you feel that there are enough resources in your area for IBD patients?
    a) Yes
    b) No

10. Do you follow a certain diet?
    a) Yes
    b) No
        i. If yes, please name the diet
        _____

11. Do you feel like you have a good support system?
    a) Yes
    b) No

Using the scale below please circle the number that best represents your confidence level of IBD.
Very Poor = 1 Poor= 2 Fair= 3 Good= 4 Very Good= 5

How do you rate your current Knowledge with:

12. Your medications 1 2 3 4 5

13. Managing your symptoms 1 2 3 4 5

14. Your IBD Healthy Diet 1 2 3 4 5

15. Stress management 1 2 3 4 5

16. What topics would you like to know more about?

Pre-test: IBD Knowledge

1. What is Inflammatory Bowel Disease?
    a) A bad stomach ache

b) An autoimmune disease involving the GI tract
c) Cancer of the GI tract
d) Intestinal ulcer

2. What are the two different types of inflammatory bowel disease?
   a) Ulcerative colitis and Irritable bowel
   b) Crohn's disease and duodenal ulcer
   c) Ulcerative Colitis and Crohn's disease
   d) Crohn's disease and Barrett's Esophagus

3. Is inflammatory bowel disease curable with medication?
   a) Yes
   b) No
   c) Sometimes

4. Is inflammatory bowel disease an autoimmune disease?
   a) Yes
   b) No

5. What foods should be avoided in IBD?
   a) Steak, broccoli, cauliflower
   b) Blueberries, bananas, cantaloupe
   c) Fish, chicken, white rice
   d) Pork, potatoes, squash

6. What foods are safe in IBD?
   a) Steak, broccoli, cauliflower
   b) Whole wheat bread, butter, cream cheese
   c) Chicken, blueberries, squash
   d) Ice cream, nuts, juices

7. What doctors treat IBD?
   a) Cardiologist
   b) Endocrinologist
   c) Hematologist
   d) Gastroenterologist

8. What are medications to avoid when you have IBD?
   a) Tylenol
   b) Tums
   c) Aspirin
   d) Codeine

9. Can stress affect your IBD symptoms?
   a) Yes
   b) No

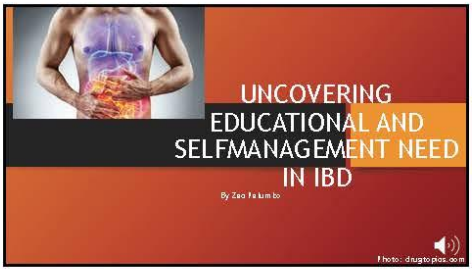
10. True or False: People with IBD can suffer from anemia?
    a) True
    b) False

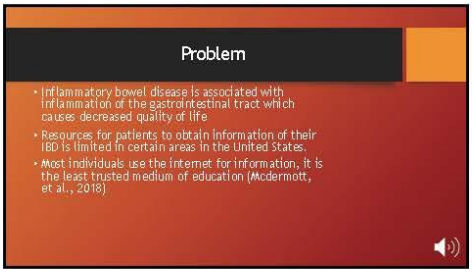
11. True or False: IBD can cause psychological symptoms?
    a) True
    b) False

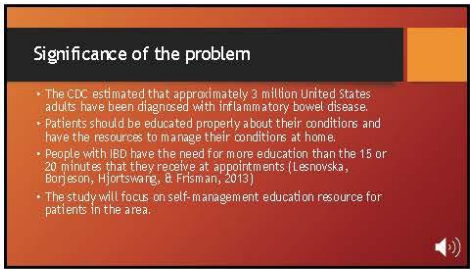
12. What are some symptoms of IBD?
    a) Coughing, sneezing, eye watering
    b) Vomiting, fever, pain
    c) Malnourishment, fever, joint pain
    d) Flatus, bulimia, hernia

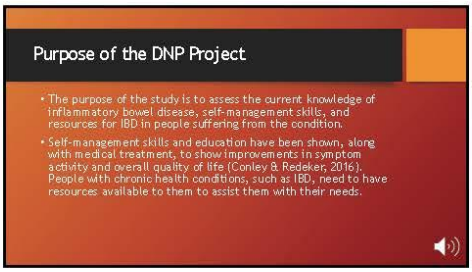
Appendix B

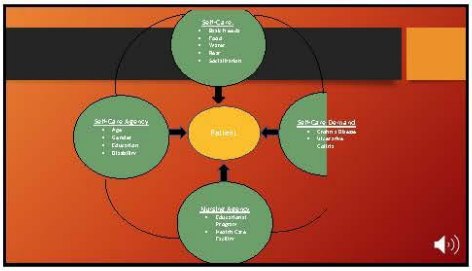
Educational Presentation











Definitions

- **Self-management:** "Is a dynamic, interactive process that captures the complexity of living with chronic illness in the context of daily life" (Conley & Redeker, 2016).
- **Inflammatory Bowel Disease (IBD):** "Is a term for two conditions (Crohn's disease and ulcerative colitis) that are characterized by chronic inflammation of the gastrointestinal (GI) tract" The inflammation causing damage to the gastrointestinal tract (Centers for Disease Control and Prevention, 2019).
- **Crohn's Disease (CD):** "Inflammation may reach through the multiple layers of the walls of the gastrointestinal tract. Damaged areas appear in patches that are next to areas of healthy tissue." Crohn's can affect any part of the gastrointestinal tract from the mouth down to the anus, however, it is mostly found in the small intestines (CDC, 2019).
- **Ulcerative Colitis (UC):** "Inflammation is present only in the innermost layer of the lining of the colon. Damaged areas are continuous usually starting at the rectum and spreading further into the colon" (CDC, 2019).

Inflammatory Bowel Disease

- Crohn's Disease and Ulcerative Colitis
- Ulcerative colitis causes long lasting inflammation and ulcerations of the lining of the colon, also known as the large intestine to the rectum.
- Crohn's disease can cause inflammation throughout the digestive tract, from the mouth to the rectum. The inflammation with Crohn's disease also can spread into deeper tissue than just the lining of the intestines (Mayo Clinic, 2019).
- S/S: blood being in stool, diarrhea, cramping and abdominal pain, weight loss and poor appetite.

Symptoms

- Physical
- Gastric tract
- Systemic:
  - Fevers, malnourishment,
- Other:
  - Eye, joint pain
- Psychological:
  - Depression, anxiety

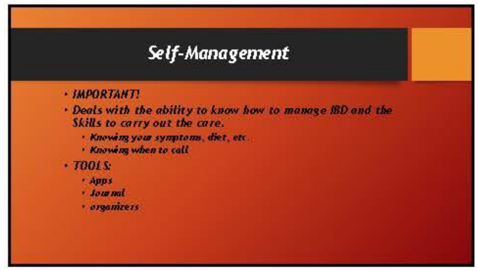
Quality of Life

- Disease has major effects on: Job, home life, relationships and overall quality of life.
- Resources can help provide support
- Ex. Dr. Office, clinic, primary care provider, online support groups, classes, nurses.
- If you need help you can find it!

Treatment

- No cure…
- Anti-inflammatory medications are used as the first line these include steroids and aminosalicylates mesalamine, olsalazine.
- Immune system suppressors (Humira, Entivo)
- Symptom Relief: anti-diarrheal medications, pain relivers, iron, calcium, and vitamin D supplements
- Diet/Nutritional support
- Surgery


Life style changes
Diet
Foods to avoid:
Steak, broccoli, cauliflower
Whole wheat bread, butter, cream cheese
Ice cream, nuts, juices
"Ok" foods to eat:
Blueberries, bananas, cantaloupe
Fish, chicken, white rice
Pork, potatoes, squash
Exercise
Low stress
Limit Alcohol


Self-Management
IMPORTANT!
Deals with the ability to know how to manage IBD and the Skills to carry out the care.
Knowing your symptoms, diet, etc.
Knowing when to call
TOOLS:
Apps
Journal
organizers


Resources
Social/Family
Peers/Friends
Education
Dieticians/Nutritionists
Technology
Telehealth
Online support groups


References
American College of Gastroenterology. (2019). What is a gastroenterologist. Retrieved from American College of Gastroenterology: https://gi.org/patients/gi-health-and-disease/what-is-a-gastroenterologist/
Cambridge University Press. (2019). Support. Retrieved from Cambridge Dictionary: https://dictionary.cambridge.org/us/dictionary/english/support
Centers for Disease Control and Prevention. (2019, March 21). Inflammatroy bowel disease. Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/ibd/data-statistics.htm
Conley, S., & Redeker, N. (2016). A systematic review of self-managment interventions for inflammatory bowel disease. Journal of Nursing Scholarship, 118-127.
Crohns and Colitis Foundation. (2019). Mid-america chapter. Retrieved from Crohns and colitis foundation: https://www.crohnscolitisfoundation.org/chapters/midamerica
Dahlhamer, J. M., Zammitti, E. P., Ward, B. W., Wheaton, A. G., & Croft, J. B. (2016, October 28). Prevalence of inflammatory bowel disease among adults aged > 18 years- united states, 2015. Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/mmwr/volumes/65/wr/mm6542a3.htm


References Cont.
Todorovic, V. (2014). Holistic support for IBD patients. Independent Nurse Vol. 2013, No. 2.

Appendix C

Post Test

Creating a New Education Resource for Patients with Inflammatory Bowel Disease

NOTICE: If at any point in the study you feel you need to drop out, you may. Your answers do not influence your chances in the drawing.

Please answer the following questions the best you can

Post-test: IBD Knowledge

1. What is Inflammatory Bowel Disease?
   a) A bad stomach ache
   b) An autoimmune disease involving the GI tract
   c) Cancer of the GI tract
   d) Intestinal ulcer

2. What are the two different types of inflammatory bowel disease?
   a) Ulcerative colitis and Irritable bowel
   b) Crohn's disease and duodenal ulcer
   c) Ulcerative Colitis and Crohn's disease
   d) Crohn's disease and Barrett's Esophagus

3. Is inflammatory bowel disease curable with medication?
   b) Yes
   c) No
   d) Sometimes

4. Is inflammatory bowel disease an autoimmune disease?
   b) Yes
   c) No

5. What foods should be avoided in IBD?
   b) Steak, broccoli, cauliflower
   c) Blueberries, bananas, cantaloupe
   d) Fish, chicken, white rice
   e) Pork, potatoes, squash

6. What foods are safe in IBD?
   b) Steak, broccoli, cauliflower
   c) Whole wheat bread, butter, cream cheese
   d) Chicken, blueberries, squash
   e) Ice cream, nuts, juices

7. What doctors treat IBD?
    b) Cardiologist
    c) Endocrinologist
    d) Hematologist
    e) Gastroenterologist

8. What are medications to avoid when you have IBD?
    b) Tylenol
    c) Tums
    d) Aspirin
    e) Codeine

9. Can stress affect your IBD symptoms?
    b) Yes
    c) No

10. True or False: People with IBD can suffer from anemia?
    b) True
    c) False

11. True or False: IBD can cause psychological symptoms?
    b) True
    c) False

12. What are some symptoms of IBD?
    b) Coughing, sneezing, eye watering
    c) Vomiting, fever, pain
    d) Malnourishment, fever, joint pain
    e) Flatus, bulimia, hernia

Post-survey

1. Did you like the presentation?
    a) Yes
    b) No
        i. What did you like or what would you change?

    _____

2. Did you find this helpful?
    a) Yes
    b) No

3. Did you learn something from the presentation?
    a) Yes
    b) No

4. Do you have any questions? If so, please list them.

   _____

5. Would you like more information? If so, what topics would you like?

   _____

6. Would you be willing to participate in a project like this again?
   a) Yes
   b) No

7. Would you attend a monthly class/support group if you had access?
   a) Yes
   b) No

8. If you could choose a resource to have what would it be?

   _____

9. What would you like to learn about with IBD?
   a) Medications
   b) The condition itself
   c) Diet
   d) Other _____

10. What resources would you like to have available to you?
    a) Support group
    b) Education
    c) Apps
    d) Other_____

Using the scale below please circle the number that best represents your confidence level of IBD.
Very Poor = 1 Poor= 2 Fair= 3 Good= 4 Very Good= 5

How do you rate your current Knowledge with:

1. Your medications 1 2 3 4 5

2. Managing your symptoms 1 2 3 4 5

3. Your IBD Healthy Diet 1 2 3 4 5

4. Stress management 1 2 3 4 5