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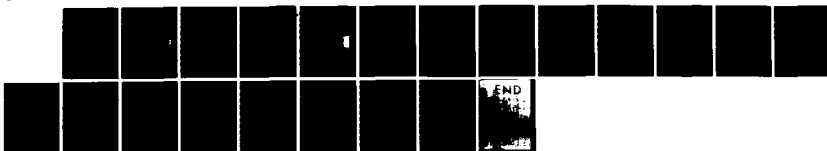
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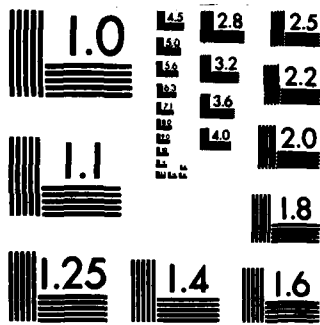
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ABSTRACT

Title of Seminar Paper: Helping Patients Cope with Inflammatory Bowel Disease

Kathleen Anne Roberts, Master of Science, 1984

Seminar Paper directed by: Karen Kleeman, RN, PhD, Assistant Professor, Medical Surgical Nursing

Two million Americans are presently diagnosed as having inflammatory bowel disease; yet health care professionals know little about it, its signs, symptoms, and associated sequelae. This article summarizes differential diagnosis, treatment, and some of the problems patients with inflammatory bowel disease live with for a life time. Strategies for enhancing patient coping are discussed and specific ways in which nurses can facilitate patients' coping are described.

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HELPING PATIENTS COPE WITH INFLAMMATORY BOWEL DISEASE

by

Kathleen Anne Roberts

**Seminar paper submitted to the Faculty of the Graduate School
of the University of Maryland in partial fulfillment
of the requirements for the degree of
Master of Science
1984**

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Two million Americans are presently diagnosed as having inflammatory bowel disease; yet health care professionals know little about it, its signs, symptoms, and associated sequelae. This article summarizes differential diagnosis, treatment, and some of the problems patients with inflammatory bowel disease live with for a life time. Strategies for enhancing patient coping are discussed and specific ways in which nurses can facilitate patients' coping are described.

Helping Patients Cope with Inflammatory Bowel Disease

Despite the fact that there are at least two million Americans with Inflammatory Bowel Disease, nurses know very little about the disease or its effect on patient's lives. Nor is it widely known that Inflammatory Bowel Disease differs significantly from Irritable Bowel Syndrome or "spastic colon/colitis".

Inflammatory Bowel Disease (IBD) identifies a class of intestinal disease with unknown etiology and similar symptoms and complications that is usually first diagnosed in young adults aged 17-27. Ulcerative colitis and Crohn's disease are the two diseases included in this class. Ulcerative colitis (UC) causes a chronic inflammation and ulceration of the inner linings of the colon and rectum. Symptoms of UC include progressive loosening of the stool that becomes bloody, that is accompanied by crampy abdominal pain and tenesmus. Patients may also experience arthralgias and skin lesions. Diagnostics include air contrast barium enema, flexible sigmoidoscopy and biopsy. The mucous membranes of the colon are finely granular and friable with scattered hemorrhagic areas. As the disease progresses the mucosa breaks down, turning red and spongy, dotted with blood and pus-oozing ulcerations. Microscopic examination of the tissue shows crypt abscesses and nonspecific acute and chronic inflammation. Ulcerative colitis affects men and women equally, and 15-20% of patients have a family history of the disease (National Foundation, 1982).

Crohn's disease, also known as regional enteritis, granulomatous colitis, and ileocolitis, is like UC in that it is a chronic inflammation of the bowel with unknown etiology. It affects caucasians more often than nonwhites, and Jews more often than non-Jews; men more than women (Schlachter, 1980). Crohn's is not limited to the colon and rectum though. It can occur anywhere in the intestinal tract although more often is found in the ileum and/or colon. Presenting symptoms of Crohn's disease can differ. More than half of the patients state that pain was their first symptom, that is, a vague cramping localized to the periumbilical area or to the right lower quadrant. The other half present with diarrhea and often fever, anorexia, and weight loss. Arthralgias are common, and clubbing, splenomegaly, erythema nodosum or uveitis occur at times. Like UC, diagnosis is made with barium enema, flexible sigmoidoscopy, and biopsy. Crohn's disease affects all layers of the intestinal wall, which becomes very thickened. Patchy ulcerations develop on the mucosa, with transverse and longitudinal ulcers and edema giving the intestinal wall a "cobblestone" appearance. These ulcerations affect multiple areas of intestine, skipping sections of normal bowel. The deep ulceration, edema, and fibrosis cause obstructions, deep sinus tracts, and fistula formations. Anemia and malnutrition can become problems depending on location and severity of the disease. In both ulcerative colitis and Crohn's disease the incidence of cancer increases as damage to the intestine progresses. Five to ten percent of patients with IBD develop cancer after having

the disease ten years (Kroner, 1980). There is a cumulative incidence of 50-70% after 30-40 years of disease (Schlachter, 1980).

Irritable Bowel Syndrome (IBS) on the other hand differs from ulcerative colitis and Crohn's disease in that there is no pathology associated with the symptoms. IBS is a motility disorder of the small and large intestine that is associated with diarrhea, cramping and/or constipation. Symptoms are apparently brought about by periods of stress and anxiety. IBS appears to have a direct positive relationship with psychological factors such as marital discord, anxiety related to children, loss of a loved one, and other obsessional worries. On the other hand, recent studies indicate that although there is an emotional aspect to inflammatory bowel disease, it is thought to be a result of the disease, not the cause of it (Mendeloff, et. al., 1970, & Sparberg, 1982). It is this psychological aspect that is at the center of misconception about IBD. Preconceived notions about the "colitis or Crohn's personality" held by the public and many health care professionals only serves to place guilt on patients with the disease and make coping with their chronic illness more difficult.

Inflammatory bowel disease is like most other chronic illnesses in that the symptoms and medical regimines imposed by the disease force patients to make many changes in their daily lives, activities, and relationships. Diarrhea imposes the most restrictions on the lives of those with the disease. Because the intestinal tract is swollen and inflamed and/or bleeding, absorption of nutrients and fluids is

impaired. Uncontrollable diarrhea (8-10 stools per day) is not uncommon. Patients with the disease think twice about leaving close proximity to a bathroom. When they do leave home they often plan their routes and destinations around the availability of a bathroom. Elimination functions, though normal, are rarely discussed, and patients with the disease are embarrassed by the constraints their disease places on them.

Anemia and malnutrition also place constraints on their lives. Patients complain of constant lethargy and weight loss, they just can't muster up enough energy to do anything. This is further complicated by the fact that many patients don't eat because eating leads to bowel movements and less control over their lives.

Treatment of ulcerative colitis and Crohn's disease is quite similar. Anti-inflammatory drugs Azulfidine and prednisone are the drugs of choice in the acute treatment of the disease. Azulfidine is taken daily even during remissions and patients are ideally weaned from the prednisone as the inflammation decreases. If the disease is located in the lower colon and rectum, cortisone enemas may also be used daily. Lomotil or Imodium are taken as antidiarrheals. Diet plays a part in controlling the disease only in as much as it effects symptoms. Those foods that exacerbate cramping and diarrhea are eliminated from the diet. Foods high in fiber and ruffage are eliminated only when strictures of the small and large intestine pose a threat of obstruction (more common in Crohn's disease than ulcerative colitis). Surgery is indicated in 50-70% of patients with IBD because of life threatening

complications. Surgery may include bowel resection, colostomy or ileostomy. Though considered a cure for people with ulcerative colitis, surgery is palliative for patients with Crohn's disease because the disease usually recurs.

Besides taking medications for the rest of their lives, the cost of the medications places further burdens on the patient and his family. The average cost/month for medications alone is \$80-\$120 (Staff, 1983). Medical insurance coverage is difficult to obtain after a diagnosis of IBD, and costly if and when it is obtained. The financial aspect of the disease along with the social stigma and personal constraints it places on a person's life make living with IBD difficult. Patients not only cope with the disease's effect on them as individuals, but its effect on their relationships with others as well.

Nurses can have an impact on patients with inflammatory bowel disease by helping them cope with their disease. The goal of nursing care of a patient with a chronic disease like IBD is to help them overcome feelings of guilt, powerlessness and failure, and to allow them to achieve a sense of control over their lives. This goal can be reached by first, assessing the patient's coping style, and then supporting those strategies or styles that increase their sense of control and enable them to reach the goal of "effective coping."

There are three basic coping styles or strategies utilized by patients with chronic illness. 1) Approach, 2) Avoidance, and 3) Non-specific defenders. Approach behaviors include tackling, or actively

fighting the illness, and engaging in therapy. Patients exhibiting approach behaviors may also seem overly concerned with the details of therapy. They question everything concerning their treatment and disease.

Avoidance strategies include cognitive styles that minimize the perceived threat that the patient's illness causes. Defense mechanisms such as denial, projection, and repression are used as well as strategies such as ignoring, rationalizing, and selective inattention to the facts or consequences of the illness. Non-specific defenders use combinations of approach and avoidance strategies (Miller, 1983). These styles or strategies can be identified by noting the range of behaviors the patient utilizes during the assessment period. The patient's use of any of these strategies can be effective as long as the strategy leads to 1) containment of guilt, fear, anxiety, and grief, 2) generation of hope, 3) enhancement of self-esteem, 4) maintenance of relationships with others, and 5) improvement or maintenance of a state of wellness. It is important to remember in assessing patient's strategies, that the nurse must not make a value judgement about the appropriateness of those strategies. The goal is effective coping, not how it is achieved.

Patients with IBD utilize approach strategies most often. Research indicates that patients with IBD are often very intelligent, inquiring and well motivated individuals. They tend to ask more questions, have specific ideas regarding their disease and its therapy, and often have read extensively about the disease (Mendeloff, et. al., 1970, & Sparberg,

1982). The nurse should encourage these qualities in the patient and not be threatened by the patient's assertive nature and aggressive use of approach strategies. This use of approach strategies should be assessed as a positive attribute and built upon in helping patients learn to cope with their disease. Instead of being threatened by the patients' knowledge, the nurse should utilize this knowledge to increase her own understanding of the disease and to use patients' knowledge bases as power resources, allowing them more control over their environment and allowing them to make certain decisions concerning their care. Such decisions might include medication times, scheduling tests around usual "bathroom times" as much as possible, and patient record keeping of intake and output. Patients should be made to feel that they have as much to contribute to their plan of care as the nurse. People who have lived with IBD for any length of time often will tell health professionals that certain medication and meal times make it easier for them to control their diarrhea and carry out their daily activities. Giving patients some control over their environment decreases anxiety, increases self-esteem, and allows for maintenance of relationships with others.

The nurse should work with family members as well as the patient. Family coping strategies need to be assessed just as the patient's are because family support networks act as a power resource for the patients. The support and acceptance patients receive from their family/social network has been found to have a positive correlation

to patient's morale, self acceptance and coping ability (Dimond, 1979). The family also needs to understand that their reactions to the patient's illness play a big part in how the patient feels about himself. If the patients feel that the people who love them are repulsed by their disease, they (the patients) may be more apt to shy away from relationships with others. For "if the people who love me can't stand me, how can anyone else?" The symptoms or sequelae of the disease effects family members too. Their plans are altered by their family member's symptoms. Family activities are planned around the patient's episodes of diarrhea and/or stamina, or are done without the patient. This can serve to increase the patient's feelings of guilt and loneliness and frustrates family members.

After initial assessment, some aspects of the nursing plan might include reinforcing coping strategies, exploring past achievements with the patient and family, and assistance in planning for any changes that might occur. Realistic goal setting should be a top priority. Helping to transfer past successes to present problems is one way to empower patients with a sense of hope and a feeling that the disease can be coped with.

The most difficult aspect of living with inflammatory bowel disease is facing the chronicity of the disease. With the most advanced scientific method, no one has yet discovered what causes IBD, and treatment only helps control symptoms, not cure them. Facing a lifetime of symptoms, medications, and the increased risk of cancer (200 times that of the

general public) may seem impossible for patients to do. The nurse can help the patient tackle this seemingly formidable task by breaking it down into small steps, each of which the patient may be more able to handle. Encourage patients to do what works for them. Suggest postponing meals or eating lightly if travel is planned shortly after the planned mealtime. Peristalsis will be decreased and the chance of an accident will also be decreased. Timing of antidiarrheals and cortenemas may also help in controlling some of the symptoms. Inform the patient what steps are necessary to decrease the risk of cancer. Annual flexible sigmoidoscopy or colonoscopy and barium enema every 3-5 years unless otherwise indicated will allow the patient's physician to take the necessary steps if changes in intestinal mucosa should occur.

Probably the most helpful suggestion a nurse can make is that the patient contact the National Foundation for Ileitis and Colitis (NFIC). The NFIC offers educational programs as well as support groups for singles and couples. These support groups' membership is similar to that of Reach for Recovery (mastectomy patients) and the Ostomy Association. They consist of people with Inflammatory Bowel Disease. Members support one another by sharing coping strategies, successes, and failures. They also sponsor education programs for themselves and the community, to increase knowledge and awareness about the disease, and disseminate results of recent research and new treatment modalities. The singles support groups work together in dealing with problems

unique to single people. Subjects such as dating, social relationships, sexuality, and career planning are discussed. The couples group discusses many of the same topics, but with the married couples concerns as their focus. These groups are successful because they consist of people who "know". They help one another through the sharing of practical experience and knowledge. Members from both groups also visit patients with the disease while hospitalized if requested to do so. Talking with others with the same disease and comparing notes and coping strategies can greatly increase the patient's self-esteem and feelings of control.

Most metropolitan areas have local chapters of NFIC, and free information is available to patients with IBD from the national headquarters as well as the local chapters. Patients can find out about local chapters and request printed information by contacting The National Foundation for Ileitis and Colitis, Inc., 295 Madison Ave., New York, N.Y. 10017. The NFIC is probably the best resource available to people with the disease and is actively engaged in supporting research in IBD.

The nurse's role in caring for the patient with inflammatory bowel disease is primarily one of a facilitator. Most patients have power within themselves to cope with the challenges which the disease presents. Often what they need is someone to define and describe that power and existing strengths, and to discuss options with them that they may not have thought of before.

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