Inflammatory Bowel Disease Nurse

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Patients affected by inflammatory bowel diseases (IBDs) are complex patients with various problems from a clinical and psychological point of view. This complexity must be addressed by a multidisciplinary team, and an inflammatory bowel disease nurse can be the ideal professional figure to create a link between doctor and patient.

Crohn's disease communication economy education fistulas IBD

1. Introduction

Inflammatory bowel diseases (IBDs) are a group of diseases characterized by the presence of chronic inflammation in the absence of an infectious etiology. The main diseases included in this group are Crohn's disease (CD) and ulcerative colitis (UC). These pathologies involve chronic inflammation of the intestine, characterized by phases of quiescence and phases of flare-up of the disease. The most common symptoms are abdominal pain, vomiting, diarrhea, flatulence, blood in the stool, frequent urge to evacuate with a sense of incomplete bowel emptying (tenesmus), and weight loss [1].

Since IBD is a systemic disease that can involve multiple organs or systems, patients with IBD often also have extraintestinal manifestations. In particular, joints, skin, and eyes are affected. The biliary tract, lungs, pancreas, and vascular system may be involved less frequently [2].

The patient with IBD, from a clinical point of view, is a complex patient, to be treated from a multidisciplinary point of view, namely, from a clinical point of view (diagnosing the disease, monitoring and treating signs and symptoms of the disease) and also from a psychological point of view. While many people with IBD are able to lead reasonably normal lives, an audit revealed that 88.5% of people with the disease feel that their quality of life is affected to some extent by the diagnosis and ongoing nature of the condition [3]. IBD often has an unpredictable course, with some patients experiencing rapid-onset intestinal and other symptoms exacerbations. These flare-ups can be very serious, require urgent care and sometimes hospitalization, and can even be life-threatening.

It has been suggested that important elements of care for IBD patients include quick access to clinics and providing adequate time to allow for discussion, explanation, information, and counseling; patients place a very high value on empathy, compassion, and interest [4]. Loss of energy, loss of control, low body image, isolation and fear, failure to reach full potential, and lack of information are the main concerns of people with IBD [5]. Patients with IBD who are parents of young children face many anxieties about their parenting, especially when they are unwell or hospitalized, and clearly need more practical help and support [6]. The patient wants to be seen as an individual,

not as a diagnosis. They also want their experience with their condition to be recognized rather than ignored [7]. These psychosocial problems are often not the primary concerns of physicians, who, in their “medical model”, may focus more on diagnosis, disease treatment, and physical symptom management. It has been suggested that nurses are better suited to help and support patients with these problems [8] and that the team’s multidisciplinary approach should provide a more comprehensive care package. From these needs, the figure of the IBD nurse was born.

2. IBD Nurse: Definition and Diffusion

The IBD nurse is a nursing figure who accompanies the patient with IBD in the organizational management of its care path. It has been advised by the British Society of Gastroenterology that the role of the IBD nurse practitioner should include several elements [9]:

- Connection between the patient and all members of the multidisciplinary team (and with other figures, if appropriate);
- Holistic support for the patient and their family in both the hospital and the community;
- Services managed by nurses: from a clinical point of view, telephone assistance, rapid triage, and organizational management of follow-up appointments;
- Support groups;
- Audit and research systems (e.g., patient database);
- Teaching and therapeutic education to patients, families, and other health professionals.

This nurse practitioner is now very widespread in northern European countries (mostly in the United Kingdom) and also in Canada and the USA [10]. This figure is prevalent in the most economically developed countries with very efficient healthcare: taking the European continent as an example, there is a greater diffusion of this nurse in Western Europe than in Eastern Europe. It is highlighted that specialist nurses play a very important role in reducing the psychological and emotional burden of IBD patients in these countries compared to Eastern European countries [11].

Today, in southern Europe, a nurse dedicated to IBD is an increasingly present reality in third-level centers. Where present, this nurse represents the reference point for every IBD patient under treatment, especially if in biological therapy.

The IBD nurse deals with various aspects of patient care, from communication and therapeutic education to the patient to the management of more complex problems such as fistulas or ostomies, passing through aspects of daily life that could influence the course disease, such as diet and sexuality.

3. Impact of Disease on Patient

In addition to symptoms such as diarrhea and fatigue, IBD commonly causes psychological distress to patients. The main concerns relate to the uncertain origins and course of the disease, execution of any surgery and/or creation of an ostomy, concern of not being able to reach the full potential of life, loss of bowel control, being a burden to others, production of unpleasant odors, and distortion of body image (due to, for example, the presence of an ostomy). Hospitalization can aggravate concerns about the potential for personal fulfillment by causing unwanted forced absence from work or studies.

Despite the fact that it is a major concern, IBD-related incontinence is rarely mentioned by patients to their doctor, but incontinence remains a major fear. According to new research, up to 74% of people with IBD experience fecal incontinence, which is not always linked to flare-ups [12]. During hospitalization, the problem of incontinence is not lessened, as a relapse is likely and the toilets can be shared among several patients, thus limiting their availability. The urgency can be serious, with some patients reporting a time delay of less than a minute between the urge in their bowels and the actual need to defecate. Loss of bowel function is so worrying that many IBD patients make a point of knowing where the closest bathroom is [13]. IBD nurses may provide empathic support and may be able to allow faster/easier access to facilities. In the event of an incontinence episode, discrete treatment and preservation of the patient's integrity are critical.

Health-related quality of life (HRQoL) is affected by IBD in both remission and relapse. While the effects have not been completely demonstrated, psychological intervention or therapy assistance could be useful for patients who are showing higher levels of concern [14]. Despite remission, underlying disease-related issues such as extraintestinal manifestations, fatigue, and sleep disorders may have an effect on HRQoL.

Patients affected by IBD also find that their illness has an effect on many facets of their lives, including relationships, education, socialization, and work. In a major European study conducted in partnership with patient organizations, more than 50% of patients with IBD indicated that their IBD had forced them to take time off work in the previous year, and almost 50% said that their IBD had stopped them from having a romantic relationship [15]. Furthermore, patients in this study often thought that their quality of life was not adequately discussed during visits as half reported that they could not talk about anything critical during a visit for their condition.

Many patients profit from interacting with those who are dealing with similar health issues. Sharing your story with people who "get" what it is like to live with a disease can be a source of vital social, mental, and psychological support [16]. Nurses may provide information about patient organizations and support groups. These are critical in offering specific, effective, and empathic support to people who are coping with a new diagnosis or complications from an existing disease.

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