PATTERNS OF INFORMATION-SEEKING OF PATIENTS NEWLY DIAGNOSED WITH INFLAMMATORY BOWEL DISEASE: A DESCRIPTIVE STUDY

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ABSTRACT

The purpose of this study is to describe the patterns for seeking and using four main sources of information by patients with inflammatory bowel disease (IBD) who meet their gastroenterologist for the first time, and to assess their level of satisfaction and reassurance with the information sources used. An online survey developed from the literature review and in collaboration with physicians and a representative of a Canadian IBD patient association was posted on the Crohn's and Colitis Foundation of Canada website. It was completed by 210 IBD patients. A descriptive analysis of the results was performed. Eighteen patterns of information seeking were identified. Nearly half of the patients used at least two sources of information, in addition to their gastroenterologist. The Internet was widely used by patients before the first appointment with the gastroenterologist (61%), and even more so after this visit (92%). Patients experienced the greatest satisfaction with print documents and other healthcare professionals (HPs, i.e., nurses and dieticians). More than half of the patients were not reassured (57.5%) and had more concerns over their illness from the answers provided by their gastroenterologist (64.6%). This study shows IBD patients naturally turn toward various sources of information, thereby reinforcing the relevance of a multidisciplinary or multimodal approach. A combination of written information, the Internet, face-to-face education and reassurance appears essential to meet their information needs and deal with their concerns

Keywords*: patient; information needs; source of information; satisfaction; multidisciplinary approach; inflammatory bowel disease*

1. INTRODUCTION

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nflammatory bowel diseases (IBD) combine various disorders that affect the intestines and the digestive tract (from the mouth, through oesophagus, to the stomach and intestines, and to the anus). The most common forms are Crohn's disease (CD) and ulcerative colitis (UC), which are both characterized by an abnormal response of the immune system that can cause ulcers, inflammation and bowel injury (Cronh's and Colitis Canada, 2018; Seyedian *et al.*, 2019). IBD is a chronic condition that significantly impacts the patients' quality of life. In addition to physical symptoms such as diarrhea, loss of bowel control and abdominal pain, IBD is known to impair relationships and family planning, professional activities or employment and mental well-being, including self-esteem and body image (Daher *et al.*, 2019; Jones *et al.*, 2019). It is often diagnosed at younger ages, from 15 to 35, and thus disrupts most of the patients' lives (Seyedian *et al.*, 2019).

As the manner in which patients perceive their illness affects their ability to cope with IBD, strategies and interventions that support more realistic views of the condition and the management of its medical implications (i.e., education, awareness raising or information) can help decrease their psychological distress and improve their quality of life (Jones *et al.*, 2019; McCombie *et al.*, 2015; Sarwan *et al.*, 2019; Zhang *et al.*, 2016). Patients' needs for information vary throughout the course of the illness, but is