

INFLAMMATORY BOWEL DISEASE, SOCIAL IMPACTS AND QUALITY OF LIFE: A LITERATURE REVIEW

DOENÇA INFLAMATÓRIA INTESTINAL, IMPACTOS SOCIAIS E QUALIDADE DE VIDA: UMA REVISÃO DA LITERATURA

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Abstract. Inflammatory bowel disease (IBD) is a continuous total or partial inflammation of the digestive tract, with Crohn's disease and ulcerative colitis being the most common forms of presentation. The most frequent signs and symptoms consist of abdominal pain, fatigue, bloody stools, diarrhea, weight loss, and vomiting, and there may be extra-intestinal manifestations. In developed countries, an increased incidence of IBD has been observed, particularly in young people of working age, impacting their quality of life as well as physical, social and psychological aspects. This is because once diagnosed with IBD, individuals encounter coping challenges, difficulties in acceptance, and lifestyle changes. Therefore, we sought to analyze the social impacts and quality of life of patients diagnosed with Inflammatory Bowel Disease. A literature review was conducted in PubMed, SciELO, BVS and LILACS databases, 20 articles met the established criteria, of which 10 were selected to compose the study. Articles published between 2016 and 2021 and relevant to the topic were included, and those that did not meet the inclusion criteria or did not comprise primary data, and were duplicates were excluded. The analyzed studies showed that there was a reduction in quality of life in patients with IBD, presenting as main factors associated with this restriction the disease activity, socioeconomic factors, and the patient's age. It was denoted that this negative aspect causes limitations, mainly in the biopsychosocial performance of patients with this condition. Therefore, it is noteworthy that biopsychosocial impacts result from the manifestation of Inflammatory Bowel Disease, which demonstrates the need for a qualified and humanized multidisciplinary follow-up during the evolution of these patients.

KEYWORDS: Crohn's Disease. Ulcerative Colitis. Sickness Impact Profile.

Resumo. Doença Inflamatória Intestinal (DII) corresponde a uma inflamação contínua total ou parcial do trato digestivo, sendo a Doença de Crohn e a Colite Ulcerativa as formas mais comuns de apresentação. Os sinais e sintomas mais frequentes consistem em dor abdominal, fadiga, hematoquezia, diarreia, perda de peso e vômito, podendo haver manifestações extra-intestinais. Em países desenvolvidos, observou-se aumento da incidência das DII, sobretudo em jovens em idade ativa, causando impactos em sua qualidade de vida e nos âmbitos físicos, sociais e psicológicos. Isso porque, uma vez diagnosticados com DII, indivíduos encontram desafios de enfrentamento, dificuldades de aceitação e mudanças no estilo de vida. Diante disso, buscou-se analisar impactos sociais e qualidade de vida de pacientes diagnosticados com Doença Inflamatória Intestinal. Foi realizada uma revisão da literatura nas bases de dados PubMed, SciELO, BVS e LILACS, em que, de 20 artigos que se adequaram aos critérios estabelecidos, 10 foram selecionados para compor o estudo. Foram incluídos artigos publicados entre 2016 e 2021, relevantes para a temática, sendo excluídos os que não preenchiam os critérios de inclusão, não compreendiam dados primários e eram duplicados. Os estudos analisados demonstraram que houve redução da qualidade de vida em pacientes com DII, apresentando como principais fatores associados a essa restrição a atividade da doença, os fatores socioeconômicos e a idade do paciente. Denotou-se que esse aspecto negativo provoca limitações, principalmente, no desempenho biopsicossocial dos pacientes com essa condição. Por conseguinte, é notável que impactos biopsicossociais decorrem da manifestação de uma Doença Inflamatória Intestinal, o que evidencia a necessidade de um acompanhamento multidisciplinar qualificado e humanizado durante a evolução desses pacientes.

PALAVRAS-CHAVE: Doença de Crohn. Colite Ulcerativa. Perfil de Impacto da Doença.

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INTRODUCTION

Inflammatory bowel disease (IBD) is a broad and widely used term to define an ongoing inflammation of all or part of the digestive tract. Among the spectrum of pathologies that encompass IBD, the most common forms of presentation occur in Crohn's Disease (CD) and Ulcerative Colitis (UC). The most often seen signs and symptoms of IBD are abdominal pain, fatigue, the passage of blood through the rectum, diarrhea, weight loss, and vomiting. In some cases, extra-intestinal manifestations may also occur, as well as joint and eye problems.¹

Ulcerative colitis is the most common form of IBD, being restricted to the intestinal mucosa and less susceptible to complications. Crohn's Disease, in contrast to UC, is a transmural, discontinuous inflammation that can affect any part of the gastrointestinal tract.²

The incidence and prevalence of IBD have been increasing in developed countries,

affecting more and more young people of working age and having a major impact, positive or negative, on their quality of life, related to physical, social and emotional aspects.³

Since many patients are diagnosed with IBD at a young age, coping with the disease is based on the acceptance of a lifetime of challenges and lifestyle changes, which can negatively impact physical, psychological, and social aspects. These negative impacts are directly related to the high rates of patients diagnosed with CD or UC who have or are more likely to have disorders such as anxiety and depression.⁴

The purpose of this study was to analyze possible impacts caused in social aspects and quality of life of patients diagnosed with Inflammatory Bowel Disease by gathering data and synthesizing results from several primary studies on the proposed theme.

METHODS

This is an integrative literature review in PubMed, SciELO, BVS and LILACS databases performed in July 2021. The Medical Subject Headings (MeSH) "Inflammatory Bowel Diseases" and "quality of life" and "social impacts" as well as their correspondents in Portuguese were used. The inclusion of the selected articles had as criteria: to contain information about inflammatory bowel disease, as well as focus on the social impacts and quality of life of patients diagnosed with the pathology, besides indispensable information about

the proposed theme. Articles that did not meet the inclusion criteria, did not include primary data, and duplicate studies were excluded. All articles published between 2016 and 2021, in Portuguese, English, and Spanish, and covering the theme in humans, were analyzed. The systematic review used to compose the current article was expanded by other bibliographic sources. The search, after inclusion and exclusion factors, resulted in 60 articles. At first, the titles and abstracts of the respective studies found were read, resulting in the selection

of 20 articles that met the requested criteria. Subsequently, these articles were read in

their entirety, and 10 studies were selected to compose this review.

RESULTS

Among the 60 articles found in the databases used, only 20 met the eligibility criteria after reading the titles and abstracts. After reading all of them, 10 articles were included in the review because they fit the objective of the study. All studies involved adult populations and 80% of them were conducted in European or Asian countries, and only one study was conducted in Brazil. The data extracted from the selected articles are described below.

A Danish cohort that followed 185 adult patients for about 7.6 years observed that patients in clinical remission had a similar quality of life to the background population and that its reduction is related to disease activity and socioeconomic factors such as unemployment and sick leave. The rate associated with unemployment for at least one year during the previous 3 years of study in these individuals was 12.1%. Patients who were absent during the follow-up period represented 5.6% of the CD patients and 6.5% of the UC patients. Furthermore, 22.6% of CD patients and 16.4% of UC patients had some impairment in work activities related to their bowel condition.⁵

This study is in line with a Japanese study of 172 adult patients, in which 72.1% felt stressed or pressured to take time off work. More than half (57.6%) of the participants felt fatigued at least one day a week during the most recent crisis-free period, as well as having diarrhea at least once a day, and 44.8% had bowel urgency at least one day a week. The biggest impact of these factors was noted on participation in social work

activities, followed by reduced motivation to work. In addition, patients with Chron's disease seemed to feel more tired during flares and tended to miss work more often due to their disease.⁶

Furthermore, a study of Cypriot patients with IBD found that patients with Chron's disease had lower overall and specific scores on all dimensions, indicating a worse quality of life in patients with this condition compared with Ulcerative Colitis.⁷ In the USA, a study of adults with IBD showed impairment in several domains of quality of life such as pain interfering with daily life, physical functioning, satisfaction with social role, anxiety and depression, among which CD patients had worse scores in physical functioning and pain interfering with daily life.⁴ In contrast, concerning psychosocial variables, an Israeli study of 122 patients with UC and 305 with CD showed that the rate of psychological symptoms was higher in UC, further evidencing the need for adapted psychotherapies.⁸

Similarly, an Italian cohort, which recruited 109 IBD patients of both genders and over 18 years of age, noted that patient-reported gastrointestinal symptoms, especially stomach pain, diarrhea and bloating were associated with psychological distress, depression, sleep disturbance, fatigue and anxiety. In addition, symptoms significantly impacted the social dimension, affecting satisfaction with participation in social roles and physical functions.⁹

It was also observed that the reduction in quality of life in IBD patients

was related to factors such as gender, age, and marital status, such that older people had higher scores in the psychological dimension.⁷ In line with this statement, an Israeli cohort of 148 individuals with UC demonstrated that older patients and those with better socioeconomic conditions had a better quality of life, while young people and those with worse socioeconomic conditions had lower quality of life and more psychological stress. In addition, patients with family relationship problems had higher rates of disease activity and psychological stress. Overall, Health-Related Quality of Life in these individuals was rated as moderate by the two scores used.¹⁰

Consonantly, a Spanish study of 436 patients diagnosed with UC, the majority of whom were men with a mean age of 46 years, showed that 79.3% of them reported that UC prevented them from leading a normal life and 76.1% had their quality of sleep impaired.

DISCUSSION

The present study analyzed the knowledge produced and related to the impact on the quality of life of individuals with Inflammatory Bowel Disease, identifying repercussions in the physical, psychological, and social domains. Despite the variations found in the studies, all indicated a deficit in some aspect that affects the quality of life, which may be the result of cultural variations, response to treatment, social aspects, and health care.

IBD has direct consequences on people's well-being, a fact associated with the presence of intestinal and extraintestinal symptoms and the frequent need for hospitalizations, admissions, and treatment. The negative aspects of this condition

In addition, concerning emotional impacts, 38% noted that UC reduced their self-confidence. Depression (26.9%) and anxiety (26.1%) were the most commonly reported symptoms as "often or mostly", being more common in women and those with a longer duration of illness.¹¹

Brazilian study of 71 patients, mean age 46.5 years, revealed that although 70% of the patients rated their quality of life as "good" or "very good", they scored lower when compared to the general population. Moreover, systemic symptoms and emotional aspects presented lower scores among the parameters evaluated.³ In contrast, a Portuguese study, which used the same questionnaire with 38 patients, showed that individuals with IBD evaluate their quality of life as reasonable (45.80%), with higher values in the systemic symptoms parameter and lower in the social aspects dimension.²

are commonly found in the educational, professional, social, and family spheres of these patients.² How the patient deals with the situation after the diagnosis is also a factor that interferes with quality of life since it is determinant in defining how the patient will be psychologically and socially affected by the disease.¹² Those who negatively understand their disease are more likely to experience reduced quality of life and impaired physical and psychological health. This situation is more common in long-term sufferers and in those who experience a greater number of symptoms.¹³

People affected with IBD find themselves in a situation that implies a change in habits and behaviors due to the

need for short-, medium-, and long-term adaptation to living with this condition. In the active phase of the disease, when symptoms are exacerbated, the effects are even more disabling and detrimental to the quality of life.² More severe disease can lead to greater psychological suffering and greater difficulty in adaptation, considering that during crises individuals tend to adopt emotional coping skills that result in poor psychosocial functioning.^{12,13}

One of the biggest challenges among these individuals is the physical symptoms of IBD, including pain, frequency of bowel movements, urgency, and diarrhea, which cause patients to plan all social activities in advance by knowing the location of bathrooms. Individuals often apply self-management skills that they have developed over time with the disease. Many individuals experience the lack of support, whether from family or friendships, as one of the adversities that reinforces social isolation, psychological fragility, and diminished educational and professional opportunities.¹

Another important issue concerns the prevalence of depression and anxiety in IBD patients. There is evidence that the disease is associated with higher rates of anxiety and depression compared to the general population, and depression is intrinsically linked to decreased quality of life in IBD patients.¹⁴ This is mainly due to four main areas of patient concern: impact of the disease, treatment, intimacy, and stigma. The impact of the disease is reflected in the risk of developing an eating disorder and in insomnia and fatigue, affecting the physical and psychological well-being; as for the treatment, some patients are afraid of the biological therapy potential side effects, corroborating the anxiety; on the other hand, intimacy and stigma are related to

body dissatisfaction, lack of interest in sex and the internalization of negative beliefs about their disease, which can exacerbate symptoms of anxiety and depression.¹⁵

Moreover, depression and the presence of psychiatric disorders were associated with decreased adherence to IBD treatment, which is extremely important for the short-term relief of disease activity and prevention of complications. Thus, early identification and psychotherapeutic intervention, through cognitive-behavioral therapy, for example, in the course of anxiety and depression in patients with IBD are essential to improve adherence and thus the long-term outcomes of individuals.¹⁴

In addition to these aspects, impacts have also been demonstrated in the sexual health of individuals considering physical, emotional and social aspects. The main predictor of reduced quality of life associated with sexual health was depression, demonstrating that the main concerns of IBD patients in this area of life are related to emotional and self-esteem issues closely associated with body image.¹⁶

Individuals with IBD report significant concerns, which should be considered in the holistic model of care because they influence the disease self-management and thus health outcomes. The main concerns were related to loss of bowel control, the risk of developing cancer, the association between stress and illness, the chronicity of the disease, and fatigue. These subjective perceptions influence the quality of life of patients, since it corroborates with psychosocial stress, favoring clinical worsening in crises.¹⁷ Moreover, fear and embarrassment were the most commonly reported emotions, associated with bowel accidents resulting from the symptoms when they occur in public, which tends to hinder the engagement and social interaction of

these citizens.¹³ Thus, it raises the need for psychological monitoring among affected individuals, in addition to the implementation

of relaxation techniques and hypnosis, to impose improvements in their welfare.

FINAL CONSIDERATIONS

Social, physical, and psychological impacts are associated with decreased quality of life for individuals with IBD due to various lifestyle changes, as well as bowel and non-bowel symptoms, hospitalization, treatment, and coping with the disease. The physical symptoms are one of the biggest challenges pointed out, since they limit opportunities to socialize in personal,

educational, and professional pillars. Another challenge strongly pointed out is the prevalence of anxiety and depression in patients with IBD, which highlights the need for monitoring by a multidisciplinary team, ranging from medical professionals, nurses, psychologists and the entire support team, aiming to obtain a holistic view of this group of patients.

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