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**Symptom Burden: A Forgotten Area of Measurement in
Inflammatory Bowel Disease**

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Key Words:	Crohn's disease, Inflammatory bowel disease, Symptom assessment, ulcerative colitis

Abstract

Inflammatory bowel disease collectively known as Crohn's disease and ulcerative colitis are chronic inflammatory diseases of the digestive tract. Periods of active and inactive disease are common along the trajectory of this illness. A range of symptoms such as fatigue, diarrhoea and abdominal pain are experienced and are often very debilitating in nature resulting in significance interference in daily life. Despite this, to date research in the area of symptoms remains an under-explored topic. This paper aims to discuss current approaches to symptom assessment in IBD and the potential to measure symptom burden in further research, in order to gain a greater understanding into the experiences of individuals with IBD.

Keywords: Crohn's disease; Inflammatory Bowel Disease; Symptoms; Symptom assessment; Ulcerative colitis;

Introduction

Inflammatory bowel disease (IBD) is a chronic inflammatory disease of the digestive tract. The two major types of IBD are Crohn's disease and ulcerative colitis. Both of these chronic illnesses are characterised by periods of active and inactive disease. Cardinal symptoms of IBD include diarrhoea, abdominal pain, weight loss, bloody diarrhoea and faecal urgency, which are considerably more intense during periods of relapsing disease. However it is now known that individuals with IBD also experience irritable bowel syndrome (IBS)-type symptoms during periods of apparent inactive disease.^{1 2 3} These symptoms can result in interference in daily life and potentially impose significant symptom burden. Recent published guidelines on the management of IBD in adults primarily used by clinicians in the United Kingdom⁴ revealed symptoms of pain and fatigue as an under-researched area of IBD. Further investigation into the understanding of the cause and impact of symptoms particularly during inactive disease states are recommended. In this paper, current approaches to symptom assessment in individuals with IBD are examined including the potential to measure symptom burden in research. The need for a more comprehensive measure that incorporates a wide range of self-reported symptoms from a multidimensional perspective of symptom burden is highlighted.

Current Approaches to Symptom Assessment in IBD

Research to date indicates that there is a high prevalence of symptoms among patients with Crohn's disease or ulcerative colitis, with some symptoms more prevalent than others. A number of

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3 epidemiological studies ^{5 6} have found that the occurrence of symptoms experienced by individuals
4 with IBD is high, although variable. These epidemiological studies are however limited due to the
5 small number of symptoms (n = 8) assessed and typically include only the physical cardinal
6 symptoms of IBD. Research now indicates that individuals with IBD also experience IBS-type
7 symptoms such as abdominal distension, mucus, pain relieved with bowel movements, change in
8 frequency of bowel movement, change in the consistency of bowel movement, straining, incomplete
9 evacuation, bowel urgency and constipation. A study by Zaman et al. ⁷ found that the occurrence of
10 these symptoms was reported by over 40% of patients with IBD. Likewise, studies by Keohane et al. ¹
11 and Minderhoud et al. ³ who sampled only patients defined as being in clinical remission found a
12 similar high occurrence of IBS-type symptoms. The prevalence rates of IBS-type symptoms have
13 been found to be three times higher in patients with ulcerative colitis in remission compared to
14 controls. ² In addition, Ansari et al. ² reported similar levels of impaired health-related quality of life
15 in individuals with ulcerative colitis in active and inactive disease states. This evidence suggests that
16 patients with IBD in remission experience potentially significant symptoms which may be overlooked
17 in clinical practice. According to Keohane et al. ¹, "Clinicians are frequently challenged to interpret
18 gastrointestinal symptoms in patients with inflammatory bowel disease, who...appear to be in
19 remission" (p. 1). Long and Drossman ⁸ differentiate between disease (pathological state) and illness
20 (subjective experiences of patients) suggesting that patients' experiences of illness may vary
21 considerably in relation to their disease status. A review by McColl ⁹ highlighted a lack of
22 concordance between healthcare professionals and patients on symptom reporting. Objective
23 assessments of symptoms are not recognised as the most appropriate approach, due to an
24 underestimation of symptoms by clinicians. McColl ⁹ concluded that symptom assessment from the
25 patient's perspective is now recommended best practice, which coincides with recent emphasis on
26 patient-reported outcomes.

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43 To date the focus of symptom assessment in IBD has been predominantly on symptom
44 severity or disease activity in terms of remission and relapse. Research on 'disease activity' in IBD
45 has been conducted for many years, with a variety of clinical disease activity indices available for
46 assessment of patients with IBD, most of which are disease specific for either Crohn's disease (e.g.
47 Crohn's Disease Activity Index, Harvey-Bradshaw Index) or ulcerative colitis (e.g. Powell Tuck Index,
48 Ulcerative Colitis Disease Activity Index, Simple Clinical Colitis Activity Index). However, previous
49 research on the assessment of disease activity with existing indices has provided little information
50 about symptom severity experiences from patients with IBD because most indices are designed to
51 provide a global severity score representative of remission or relapse of the disease. ^{10 11} In addition,
52 the limited number of symptoms assessed may not adequately capture the range of symptoms that
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3 patients with IBD may experience. A key criticism of the Crohn's Disease Activity Index, which is
4 considered the gold standard for measuring disease activity in Crohn's disease, is that it fails to
5 include a subjective assessment of systemic features, such as fatigue into its composition.¹²
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7 Furthermore, disease activity indices are completed from the physicians perspective based on
8 clinical and laboratory variables. Therefore, current symptom measures appear inadequate as
9 measures for identifying the most problematic symptoms experienced by individuals with IBD.
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11 Perhaps a multidimensional measure of symptom burden may be more suitable at providing richer
12 information on the symptom experiences of individuals with IBD.¹³
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18 **Symptom Burden Measurement: Implications for IBD**

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20 Symptom burden is a distinct measure of the experience of symptoms that incorporates the
21 physiological and psychological functioning of the individual experiencing the symptoms. The
22 concept is most commonly referred to in the oncology literature, in particular in the medical and
23 psychology literature. However, recently a growing body of literature on symptom burden is
24 apparent in the nursing literature and in the area of chronic illnesses. In 2007, Gapstur¹⁴ conducted
25 a concept analysis of symptom burden and identified five key attributes of symptom burden, namely
26 dynamic, multidimensional, quantifiable, subjective and physiological burden. Symptom burden is a
27 subjective, dynamic concept in that it is the patient's own perception of a constantly evolving
28 experience. Gapstur¹⁴ refer to symptom burden as composing of multiple dimensions including the
29 prevalence, severity and frequency of symptoms. These multiple dimensions are quantifiable or
30 measureable in nature. Gapstur highlighted some inconsistency among researchers in terms of what
31 dimensions of concept of symptom burden have been studied ranging from a measure of the
32 number of symptoms (prevalence) experienced by individuals to measuring severity and/or
33 frequency. Although Gapstur¹⁴ identified symptom distress as a related concept to symptom
34 burden, previous researchers have measured distress as a dimension of symptom burden^{15 16}, thus
35 highlighting some ambiguity surrounding the measurement of the concept.
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47 Studies on symptom burden were reviewed across a range of chronic illnesses, namely,
48 oncology, cardiac, respiratory and renal. Variation in approaches to measuring symptom burden is
49 evident in terms of assessment methodologies. There is a range of instruments used across studies
50 to investigate symptom burden which vary in the number of dimensions measured. Conceptual or
51 theoretical perspectives on symptom burden are not explicitly evident among studies, however
52 studies that measured symptom burden using the Memorial Symptom Assessment Scale (MSAS)
53 originally developed by Portenoy et al.¹⁷ for cancer patients reflect current conceptual
54 understandings of symptom burden as being multidimensional.^{14 16} Studies that have used the MSAS
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3 measured symptom burden in terms of severity, distress and frequency. Instruments used in other
4 studies such as the Edmonton Symptom Assessment System (ESAS), modified ESAS, and Dialysis
5 Symptom Indx (DSI) measured fewer dimensions than the MSAS. Likewise, the MD. Anderson
6 Symptom Inventory, which is most commonly used in oncology populations, have assessed the
7 severity of symptoms only but also incorporates item on inferences with daily living. Contrary to
8 Gapstur's ¹⁴ conceptualisation which includes symptom prevalence as a quantifiable dimension of
9 symptom burden, prevalence has not been measured as a dimension of symptom burden in chronic
10 illnesses studies, apart from epidemiological studies investigating the burden of disease in
11 populations. Prevalence data are frequently presented and provide useful information on symptoms
12 commonly experienced by individuals with similar chronic illnesses, and the mean number of
13 symptoms that individuals can experience. However, prevalence data do not contribute to a
14 measure of symptom burden. Furthermore, some disparity is evident among the type of symptoms
15 assessed in studies investigating symptom burden, with physical symptoms assessed mostly or
16 exclusively compared to few or no psychological symptoms assessed. It is known that individuals
17 with various chronic illnesses are burdened by psychological symptoms ¹⁸, therefore highlighting the
18 importance of including psychological symptoms in the measurement of symptom burden.
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30 It can be gleaned from studies on chronic illness that the quantifiable dimensions of
31 symptom burden are severity, frequency and distress. From existing measures of symptom burden
32 used in previous research studies, the Memorial Symptom Assessment Scale appears to have the
33 greatest potential as it includes each of these salient dimensions (namely, severity, frequency and
34 distress) and a broad range of both physical and psychological symptoms. However, this research
35 instrument has not been previously used in the IBD population. Considering the instrument was
36 originally developed in an oncology population, there is a need to modify the instrument by adding
37 supplementary IBD specific symptoms. Some symptoms in the original MSAS, for example hair loss,
38 are inappropriate in assessing symptom burden in IBD, whereas other symptoms such as rectal bleed
39 are cardinal to the condition. The MSAS has been previously deemed a reliable and valid scale. ^{17 19 20}
40 ^{21 22} In addition, it has been modified to be disease-specific in a number of population groups such as
41 cystic fibrosis and heart failure. ^{19 20} Therefore, following further development of the MSAS specific
42 for the assessment of symptom burden in IBD, there is a need to assess the psychometric properties
43 of the revised instrument. Given the growing body of evidence that individuals living with chronic
44 illnesses are burdened by symptoms and the recent call for more research into the area of
45 symptoms in IBD ⁴, it is now timely and desirable to investigate the level of symptom burden
46 experienced by individuals with IBD. Currently, the researcher is conducting a mixed methods study
47 investigating this topic used a modified version of the MSAS to investigate the level of symptom
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burden experienced in a sample of individuals with Crohn's disease and ulcerative colitis of varying disease activity.

Conclusion

In conclusion, symptoms are a complex phenomenon and are recognised as having adverse effects on individuals' lives. Symptoms are known to be problematic among individuals diagnosed with IBD, yet they remain an unresearched topic. There is a need for a new direction in the measurement of symptoms in future IBD research, such as the newly evolving measurement of symptom burden. To date, symptom burden is a forgotten area of measurement in IBD, compared to the growing body of literature in the area of other chronic illnesses. This multidimensional assessment of symptoms would provide a deeper understanding into the symptom burden experiences of individuals with IBD along their relapsing and remitting disease trajectory. In turn, this data may contribute to the development of new intervention strategies aimed at lowering the level of symptom burden experienced by individuals with IBD and thus improve quality of life.

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