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# Symptom burden in inflammatory bowel disease: Rethinking conceptual and theoretical underpinnings

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## Symptom burden in inflammatory bowel disease: Rethinking conceptual and theoretical underpinnings

Symptom control is fundamental to the nursing management of inflammatory bowel disease (IBD). However, symptom control can be problematic for individuals with IBD, which could result in symptom burden. Symptom burden is an evolving concept in the discipline of nursing and to date little is known about how the defining characteristics of this concept have been applied to symptom research in IBD. In this discussion paper, the concept of symptom burden and the theory of unpleasant symptoms are explored as a basis for understanding for symptom research in IBD. This is followed by a critical examination of previous symptom research in IBD. Our conclusion is that there is a need to rethink conceptual and theoretical underpinnings of symptom burden when researching IBD to take account of its defining characteristics, namely symptom severity, frequency and duration, quality and distress. Research knowledge on these defining characteristics will be important to inform nursing assessment of symptom burden in clinical practice.

**Key words:** ••.

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## INTRODUCTION

Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD), are lifelong illnesses. Over the last decade, the incidence and prevalence of IBD have significantly escalated.<sup>1</sup> There is a widespread occurrence of IBD worldwide. Prevalence rates for ulcerative colitis range from 37 to 246 cases per 100 000

persons and for Crohn's disease range from 26 to 199 cases per 100 000, with a higher incidence of IBD in northern Europe and America and lower incidence in southern Europe, Asia and developing countries.<sup>2</sup>

Inflammatory bowel disease is characterized by unpredictable periods of relapse and remission. Individuals commonly experience debilitating symptoms such as abdominal pain, diarrhoea, weight loss and rectal bleeding. These symptoms can result in disruption to their daily lives potentially imposing significant symptom burden. Nursing assessment of problematic symptoms and the identification of symptom burden are therefore integral to

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the chronic illness management of individuals with IBD. Although the concept of symptom burden has been addressed in the medical and psychological literature over many years, only recently has it been recognized as a new evolving concept in the discipline of nursing.<sup>3</sup>

The purpose of this paper is to examine conceptual literature on symptom burden and its defining characteristics. The theory of unpleasant symptoms will be examined in terms of its similarity with characteristics of the concept of symptom burden. Previous research on symptom burden in IBD is then examined to determine what dimensions have been studied. Our review of conceptual, theoretical and empirical literature is then discussed with consideration to implications for practice and future research.

## THE CONCEPT OF SYMPTOM BURDEN

For individuals with IBD, symptoms are a major part of their lives and are fundamental to nursing care particularly in the assessment stage of the nursing process. In recent years, there has been a growing interest in exploring the nature of symptoms resulting in the publication of conceptual analyses and discussions particularly in the field of oncology nursing. Work to date has focused mostly on the concepts of symptom experience<sup>4,5</sup> and symptom clusters (measure of multiple symptoms).<sup>6-8</sup> Symptom burden, although related to the concepts of symptom experience and symptom clusters, is a distinct concept.<sup>9</sup>

Guided by Rodger's method of concept analysis, Gapstur identified five key attributes of symptom burden: multidimensional, dynamic, quantifiable, subjective and physiological burden.<sup>3</sup> As a multidimensional concept, assessment of symptom burden needs to focus on frequency, severity and distress of symptoms experienced by individuals. Variation in any one or more of these dimensions characterizes the dynamic nature of symptom burden and this variation depends on factors such as the stage or prognosis of disease and treatments. Symptom burden is quantifiable therefore, permitting the measurement of symptoms that are more or less burdensome for individuals. The subjective attribute of symptom burden indicates an individual's awareness of and meaning attached to change in functioning and sensation as a result of experiencing a symptom.<sup>10,11</sup> To assess the subjective nature of symptom burden, it is necessary to glean the perspectives or self-reports of the individual experiencing the symptom;<sup>3</sup> a point also supported by other

researchers.<sup>5</sup> Finally, symptoms can impose an alternation in the physical functioning of the human body thus symptom burden can be 'physiological'.

Gapstur's analysis is important as it represents a beginning definition of the concept of symptom burden.<sup>3</sup> Although the analysis is mostly informed by oncology literature, dimensions of symptom burden seem applicable to illnesses other than cancer. According to Gapstur, continued development of the concept of symptom burden is needed.<sup>3</sup> Although not addressed by Gapstur,<sup>3</sup> one consideration for further advancing the concept of symptom burden is to develop its theoretical base. As suggested by Walker and Avant,<sup>12</sup> a concept analysis is a fundamental block of a theory but does not help to explain how various components or concepts within a theory are interrelated.

## THE THEORY OF UNPLEASANT SYMPTOMS

To date, no unified theory of symptom burden has been reported in the nursing or allied health literature. However, the middle-range theory of unpleasant symptoms developed in the mid-1990s<sup>10,11</sup> is proposed herein as relevant to explaining symptom burden in a complete and insightful way for both researchers and practitioners. According to Lenz *et al.*,<sup>11</sup> the theory of unpleasant symptoms has the potential to integrate existing information about a variety of symptoms. Although an unpleasant symptom can occur in isolation, the presence of multiple symptoms simultaneously is a more common experience for individuals experiencing illnesses. The manifestation of symptoms can vary in terms of intensity/severity, degree of associated distress, timing and quality. Intensity refers to severity and is the most frequently and easily assessed dimension of unpleasant symptoms.<sup>13</sup> For example, a pain scale can measure the intensity of pain on a scale of 0–10 with increasing scores representing increasing severity of this symptom.

The dimension of distress is the degree to which patients are bothered by symptoms experienced. For each individual, this dimension is unique as it is subjective to the meaning an individual attaches to the unpleasant symptoms.<sup>13</sup> The dimension of timing refers to the duration and frequency of symptoms, which can be classified as acute or chronic. Symptoms might fluctuate in frequency and duration over the trajectory of the disease or treatment.<sup>13</sup> The dimension of 'quality' refers to the manner in which symptoms manifest and the feelings these inflict on

individuals. Each symptom can have a number of qualitative descriptors based on sensations experienced by an individual. For example, pain can be characterized as stabbing, pounding, throbbing or sharp.<sup>13</sup> These theorists have suggested that a change in the quality of unpleasant symptoms as reported by an individual might signal a change in the disease progression or disease stage. The descriptors used in communicating the quality of unpleasant symptoms can vary from individual to individual.<sup>13</sup>

In addition to the central concept of 'symptoms', the theory of unpleasant symptoms has two further concepts: influencing factors and performance. Factors influencing symptoms are conceptualized as physiological (disease, treatment-related factors, age and gender), psychological (e.g. mood), cognitive (e.g. level of knowledge and coping skills) and/or situational (social and physical environment). Performance is the outcome concept of the theory, focusing on negative consequences of symptoms and which has multiple dimensions in relation to functional and cognitive abilities.<sup>13</sup> With consideration to all three concepts (symptoms, influencing factors, performance), the theory of unpleasant symptoms is a complex interactive model of symptom experience. However, despite its complexity, the theorists have stated that for both researchers and practitioners, the dimensions of unpleasant symptoms are measurable.<sup>13</sup>

## SYMPTOM BURDEN RESEARCH IN IBD

To date, little research has been conducted on symptom burden of individuals with IBD that takes account of conceptual or theoretical underpinnings. However, studies have investigated specific dimensions of symptom burden, most commonly, symptom severity using a growing number of disease activity indices specific to Crohn's disease<sup>14</sup> or ulcerative colitis.<sup>15</sup> Individuals with Crohn's disease have been found to experience greater symptom severity than patients with ulcerative colitis.<sup>16</sup> However, irrespective of disease type (Crohn's disease or ulcerative colitis), individuals with IBD have been found to experience greater symptom severity than healthy age-matched controls.<sup>17</sup> Disease activity indices as measures of symptom severity are of limited practical value to nursing assessment of individuals with IBD however, because they require clinical input of signs, laboratory markers including histology reports. Disease activity indices are also limited in the number of symptoms assessed, often focusing only on the classic symptoms associated with Crohn's

disease or ulcerative colitis. A further limitation is that symptom severity as disease activity is but one dimension of symptom burden. These points were addressed by researchers who developed a Survey-based Crohn's disease Activity measure of symptoms (general well-being, abdominal pain, number of loose stools per day).<sup>18</sup> However, these researchers raised concern that this index might not accurately capture disease burden.

The 'frequency' of symptoms as a dimension of symptom burden has been assessed in patients with IBD to lesser extent than symptom severity. Not surprisingly, symptoms have been shown to occur more frequently during periods of relapse compared with remission.<sup>19,20</sup> For example, a Finnish study ( $n = 2424$ ) revealed that between 34% and 41% of patients can experience weekly flare-up of symptoms for ulcerative colitis and Crohn's disease, respectively.<sup>21</sup> The duration or timing of symptoms as distinct from the frequency of occurrence<sup>13</sup> is a further consideration in researching symptom burden. There is little known to date however on the duration of symptoms experienced by patients with IBD.

Researchers have varied in the number of IBD-related symptoms assessed ranging from as few as three<sup>22</sup> to as many as 28.<sup>19</sup> Focusing on too few symptoms or just those representing classic features of ulcerative colitis (abdominal pain, diarrhoea and rectal bleeding) or Crohn's disease (abdominal pain, diarrhoea and weight loss) runs the risk of missing important data relevant to clinical assessment of symptom frequency. Interestingly, data from patient focus groups have shown that the majority of the most frequent symptoms experienced were 'novel' (e.g. stool mucus, loud bowel sounds, flatulence). These data point to the existence of multiple symptoms or 'symptom clusters', which could also contribute to symptom burden<sup>3,13</sup> but have received little attention in IBD research to date.

Symptoms of high intensity, frequency and prolonged duration might contribute to significant distress for individuals with IBD, particularly during acute exacerbations. Pain has been described as one of the most distressing symptoms of living with ulcerative colitis.<sup>23</sup> Distress associated with bowel symptoms has consistently been reported in studies, specifically relating to loss of bowel control, uncontrollable bowel sounds, bowel urgency, incontinence and unpleasant odours.<sup>24-26</sup> Frequent bowel motions and associated odours have been described as 'rotten stuff' that 'stinks'.<sup>24</sup> These quality descriptors illustrate the subjective nature of symptoms and the feelings that symptoms can inflict on individuals, as



- [6] suggested by Lenz and Pugh<sup>13</sup> in the theory of unpleasant symptoms.

## IMPLICATIONS FOR RESEARCH

As evident from the empirical literature reviewed, many researchers have studied the problem of symptoms in individuals with IBD. Research has been conducted mostly on symptom severity and to a lesser extent on symptom frequency and distress. Collectively, these areas represent some key characteristics of symptom burden as conceptually defined by Gapstur,<sup>3</sup> therefore capturing in part its multidimensional perspective. The areas of symptom burden previously studied are also consistent with some key characteristics of the theory of unpleasant symptoms.<sup>10,11,13</sup> However, previous research on the study of symptom burden specific to IBD has been piecemeal, because as already noted, one dimension has been privileged in research over others, namely severity. For a comprehensive measurement of symptom burden that is conceptual and theoretically based, future research on IBD needs to take account of all of its dimensions or characteristics.

Although there has been little attempt to measure all dimensions of the concept of symptom burden in individuals with IBD, the potential for this is evident in studies on symptom burden in other chronic illnesses. For example, the concept has been measured in individuals with cystic fibrosis,<sup>27</sup> heart failure<sup>28</sup> and cancer.<sup>29</sup> Symptom burden has been measured using various instruments including the Memorial Symptom Assessment Scale (MSAS), the Memorial Symptom Assessment Scale Short Form and the Edmonton Symptom Assessment System. All scales are reliable and valid. However, the MSAS seems particularly useful as it incorporates most dimensions of symptom burden, namely the frequency, severity and distress associated with symptoms. In the MSAS, the dimension of frequency measures 24 symptoms using a four-point Likert scale. A larger number of 32 symptoms are measured for severity and distress using a four-point Likert scale and a five-point Likert scale, respectively.<sup>19</sup> Although the dimension of timing (duration) of symptoms is not a subscale of the MSAS, this could be added to the scale and then tested for reliability.

Although the MSAS was originally developed to measure symptom burden in individuals with cancer,<sup>19</sup> the measure can be adapted to include disease-specific symptoms such as rectal bleeding, flatulence, bowel urgency and more symptoms relevant to IBD. Furthermore, the

MSAS measures symptom burden in relation to physical and psychological symptoms. Psychological symptoms included in the measure are worrying, feeling irritable, feeling nervous and feeling sad. The inclusion of psychological symptoms is important because it draws attention to symptom burden being psychological as well as physical. The MSAS as a measure of symptom burden could therefore address the current imbalance in IBD research, which has predominantly focused on physical symptoms. Although studies have measured depression and anxiety in individuals with IBD,<sup>30–32</sup> data on individual symptoms or the level of burden associated with these symptoms cannot be extracted from this research. There is a need to further understand the psychological burden of symptoms because as indicated in qualitative studies on individuals with IBD, they can experience anger, fear and worry.<sup>24,25</sup> Future qualitative research into symptom experiences of individuals with IBD is needed to add to the current body of knowledge about the psychological impact of symptoms. This research would be important to identifying problematic symptoms that could be included in the measurement of symptom burden. However, qualitative research has merit, not just for the purpose of informing measurement, but also for capturing the subjective meaning that individuals attach to their symptom burden experiences.

## IMPLICATIONS FOR PRACTICE

Symptom burden is relevant to nursing practice particularly in relation to clinical assessment. Dimensions of the concept of symptom burden<sup>3</sup> and the theory of unpleasant symptoms<sup>10,11,13</sup> are proposed herein with consideration to physical and psychological symptoms as a framework for clinical assessment with reference to the frequency, severity, distress, duration and quality of symptoms in individuals with IBD.

The dynamic nature of symptom burden<sup>3</sup> prompts the need for ongoing assessment of problematic symptoms, which is especially important in the case of IBD for which symptom control is a key goal of nursing management. Research has shown that symptoms are more problematic in disease relapse state compared with remission.<sup>20</sup>

A further consideration in the clinical assessment of symptom burden in patients with IBD is to incorporate multiple symptoms. It is possible that multiple symptoms impose greater symptom burden. Individuals with IBD typically experience the cardinal symptoms of IBD, namely diarrhoea, abdominal pain, rectal bleeding and

weight loss.<sup>22</sup> However, some research prompted the need to broaden the number of symptoms assessed to including irritable bowel syndrome-like symptoms such as abdominal distension, mucus, bowel urgency and straining.<sup>33</sup> A focus on physical symptoms only however would be too narrow a focus in the assessment of symptom burden as it is known individuals with IBD can experience psychological symptoms such as fear, worry and anger.

Nurses also need to take account of symptom burden as a subjective experience, which can vary from one patient to the next. In essence, symptom burden is the product of a specific interpretation of a symptom experience. Therefore, in practice, differences can be expected between individuals regarding how they experience the level of severity, frequency, duration, distress and quality of symptoms. Given the subjective nature of symptom burden, it is important that nurses understand the meanings that individuals attach to the symptom experiences so that care plans to manage symptoms are developed and implemented in ways that are relevant and meaningful to individuals' unique experiences.

Although assessment of symptom burden is paramount to the nursing care of individuals with IBD, there is a lack of reliable and valid clinical assessment tools available to nurses. As noted from the empirical literature, clinical indices do exist but are limited because they address a small number of symptoms and focus on symptom severity only. Clinical guidelines to support nursing assessment of symptom burden are also lacking. These deficits in current practice reinforce the need for further research, as recommended earlier in this paper. Research that is informed by conceptual and theoretical underpinning of symptom burden has the potential to enhance the practice of nursing through its application to the assessment of symptom burden in individuals with IBD.

## CONCLUSION

Knowing what is meant by a concept in terms of its defining attributes or dimensions is important to researching a concept and to applying a concept to practice situations. For example, a researcher investigating symptom burden in individuals with IBD would need to know how this concept is defined and operationalized for the purpose of measurement. Likewise, a nurse practitioner would need to know the dimensions of symptom burden for the purpose of symptom assessment of individuals with IBD. In this paper, we set out to examine conceptual and

theoretical literature of relevance to symptom burden as a basis for examining the focus of studies conducted to date on the level of burden among individuals with IBD. Previous symptom research in IBD is limited to addressing burden primarily within the context of symptom severity. Researchers need to rethink conceptual and theoretical underpinnings of symptom burden in IBD with consideration to broadening the scope of dimensions for measurement. This research and its application to practice could be guided by conceptual literature on symptom burden and the theory of unpleasant symptoms, as described in this paper.

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