# Why Studying Urgency Is Urgent

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**Abstract:** Bowel urgency, the sudden and immediate need to have a bowel movement, is one of the most widely reported and debilitating symptoms of ulcerative colitis. Urgency has a profound impact on patient well-being, often resulting in patient disengagement from education, employment, and social activities. Although its prevalence correlates with disease activity, it is present in states of both disease flare and remission. Postulated pathophysiologic mechanisms are complex, but urgency is likely a consequence of both acute inflammation and structural sequelae of chronic inflammation. Bowel urgency is not widely incorporated into clinical assessment indices or clinical trial endpoints, despite being a pivotal symptom influencing patient health-related quality of life. Addressing urgency can be challenging owing to the associated embarrassment for patients in volunteering this symptom, and its management can be nuanced in the context of a paucity of specific evidence to target it, independently of disease activity. Explicitly inquiring about urgency and integrating it into a multidisciplinary team combining gastroenterologists, psychological support, and continence services is essential to achieving shared satisfaction from treatment. This article outlines the prevalence of urgency and its impact on the quality of life of patients, describes postulated driving mechanisms, and makes recommendations for its inclusion in clinical care and research.

**Keywords**
Urgency, ulcerative colitis, inflammatory bowel disease, epidemiology

Ulcerative colitis (UC) is a complex idiopathic inflammatory bowel disease (IBD), characterized by relapsing and remitting inflammation of the colonic mucosa, extending proximally from the rectum.[1] Clinical manifestations of the disease are broad. Symptoms of disease activity typically are diarrhea (with or without mucus); rectal bleeding; and symptoms of anorectal dysfunction, including bowel urgency, incontinence, and tenesmus.[2] Symptoms of anorectal dysfunction are particularly troublesome for patients and are often associated with embarrassment or social stigma, underreported by patients in clinical consultations, and unrecognized by health care professionals.[3-5] Bowel urgency, defined as the sudden and immediate need to have a bowel movement, is frequently part of the presenting features of UC, can be present in both states of disease activity and remission, and has a high impact on patient well-being.[2,6] However, measures of bowel urgency are not incorporated into widely used clinical assessment

indices or clinical trial endpoints, despite being a pivotal symptom influencing patient satisfaction on treatment and health-related quality of life.[2,7] This article focuses on the prevalence and burden of bowel urgency in UC, characterizes postulated pathophysiologic mechanisms, and identifies areas of unmet need to drive patient-centered care in UC.

## Epidemiology of Urgency

Bowel urgency commonly occurs with, but is distinct from, fecal incontinence.[8] International surveys report a prevalence of urgency greater than 80% among patients with UC, irrespective of treatment status.[9-11] An assessment of the burden of IBD in the preceding week, using the Memorial Symptom Assessment Scale on 247 patients, identified fatigue, urgency, diarrhea, and bloating as the most common symptoms experienced by patients. All symptoms were more prevalent among patients with active disease, with urgency being the most common (84%).[12] A separate, prospective assessment of 96 UK patients with UC identified urgency as present in 85% of patients with active disease.[10] A Polish survey of patients hospitalized with UC found that among those who experienced urgency, greater than 50% reported an inability to defer the desire to defecate for more than 5 minutes, 50% reported urgency occurring at least once a day, and 70% reported a consequent worsening of their everyday functioning.[9] In a cross-sectional analysis of 576 patients with UC from the Study of a Prospective Adult Research Cohort, 31% of patients reported mild urgency and 28% reported moderate to severe urgency.[13] The presence of moderate to severe urgency was associated with the presence of rectal bleeding, stool frequency, and a raised fecal calprotectin level. During an 8-week clinical trial period in 250 patients, 83% of patients reported experiencing urgency over 3 days at baseline (71% for all 3 days), and improvement in urgency was correlated with clinical disease remission.[11] The presence of urgency is more common in patients with active disease; however, urgency may occur in patients without an increased stool frequency or rectal bleeding.[4,11,14] After adjustment for clinical variables, including rectal bleeding and stool frequency, bowel urgency was independently associated with a significantly increased risk of hospitalization, corticosteroid therapy, and colectomy. Urgency is also linked to depression, anxiety, and fatigue.[15]

The evidence base characterizing the burden of urgency in UC largely consists of cross-sectional surveys or observational epidemiologic studies. It is therefore possible that urgency is overrepresented in existing research because these study designs are subject to selection bias. Inclusion of measures of urgency into future prospective studies or clinical trial endpoints would aid a clearer understanding of the prevalence of urgency and its association with disease activity and treatment in UC.

## Impact on Quality of Life

Bowel urgency is frequently identified by patients as the most bothersome symptom of UC. In an international survey of 775 patients, 574 physicians, and 50 nursing staff members, both patients and health care professionals ranked urgency as the symptom of greatest concern, although it was reported as more severe by patients.[16] Among 502 patients with a history of moderate to severe UC in France, Germany, Italy, Spain, and the United Kingdom, one-quarter experienced bowel urgency, which was reported as the most bothersome UC symptom, often persisting when their disease was in remission.[6] Bowel urgency has a significant impact on health-related quality of life and limits participation of individuals with UC in physical exercise, education, employment, wider social activities, and sexual intimacy.[5,8,11,17-20] In an online survey, 79% of 859 adult participants reported that their IBD limited their physical activity, and 61% of those patients included the symptom of urgency as the principle reason.[17] Among 200 patients with a history of moderate to severe UC in the United States, 75% described wearing some form of protection such as pads or diapers in the preceding 3 months, 43% reported declining social activities because of bowel urgency, and 37% reported declining to take part in work/school.[18] On the contrary, an absence of urgency has been associated with a significantly improved quality of life.[21]

In qualitative concept elicitation interviews of adults with UC, 90% of participants spontaneously described bowel urgency as a common symptom that had a significant impact on their activities and well-being.[2] This included a need to incorporate the possibility of sudden bowel urgency into daily plans, to ensure prior knowledge of local bathrooms, and to be close to a bathroom.[2] The unpredictable nature of symptoms was described as emotionally distressing, with associated anxiety and embarrassement.[2,22] The reasons underlying these behaviors and feelings are probably multifactorial, but include the influence of social norms that render taboo any discussion of bowel movements, let alone a lack of bowel control in adulthood.[5] Although often well concealed, urgency and fecal incontinence, or the very fear of experiencing these symptoms, are particularly problematic for patients with UC and challenge social expectations. Bowel urgency may therefore contribute to a social stigma that shapes adaptations that can be devastating to the personal and professional lives of patients living with UC.[23] Even in the context of an absence of negative comments, the

anticipation of social disapproval can be enough to drive embarrassment and negative social behavioral changes, leading to isolation.[5] Given that UC onset typically peaks among young adults aged 20 to 40 years, which are economically productive and child-bearing years, the impact of impaired social, educational, and employment participation of patients with UC is substantial in terms of direct and indirect medical and economic productivity costs.[1,24] In Western countries, a systematic literature review has estimated the annual total economic burden of UC to be $8.1 to $14.9 billion dollars in the United States and €12.5 to €29.1 billion euros in Europe.[25] Urgency matters. Therefore, proper emphasis is warranted to address bowel urgency, which compromises the daily functioning of patients and disproportionately affects both individuals and broader society relative to other indicators of disease activity.

## Mechanisms of Urgency

The pathophysiologic mechanism underlying urgency is complex and incompletely understood. Postulated mechanisms include inflammation, intestinal dysmotility, anorectal dysfunction, and higher cerebral function.[2,26] Inflammation is an important, but not the only, driver of UC symptoms; the consequences of inflammation may result in progressive damage, hypersensitivity, and reduced rectal compliance.[27] In a prospective controlled study of rectal compliance in patients with UC and non-IBD controls, rectal compliance was significantly lower in patients with active or quiescent UC compared with non-IBD controls.[27] Given that reduced rectal compliance and altered rectal function are also present among patients with quiescent UC, urgency is unlikely to be solely attributable to active mucosal inflammation.[27,28] Other attributable factors include submucosal fibrosis and muscularis mucosal hypertrophy, which are common complications observed in chronic UC that may represent the consequences of progressive inflammatory processes on luminal wall motility and rigidity.[19,29] Furthermore, patients with UC whose rectal mucosal histopathology returns to normal also have normal rectal compliance, similar to that of healthy controls, unlike patients with persistent but quiescent microscopic changes.[27] Because normalization of histopathology only occurs in a minority of patients with UC, this function improvement is another marker of disease control, which includes a 5-fold lower relapse rate, lower risk of hospitalization or colectomy, and 3-fold reduction in the risk of neoplasia.[30] It is as yet unknown whether resolution of bowel urgency is a surrogate marker for mucosal healing.

An early study in the 1980s assessed anorectal function by measuring pressures at multiple anorectal sites under basal conditions and during balloon distension. Among 29 patients and 12 controls, bowel frequency and urgency were found to be related to poor rectal compliance and hypersensitivity in inflamed UC, with disease remission associated with improved compliance and less rectal sensitivity.[31] Reduced rectal compliance may result in increased rectal pressure and therefore increased bowel urgency. However, in a further study of 9 cases of UC flares and 17 healthy controls, patients with UC were found to be hypersensitive to rectal mechanical stimuli, without any difference in rectal compliance.[32] Anxiety and depression are also common comorbidities among patients with IBD, and the clinical consequences of the brain-gut axis offer a physiologic explanation through which psychological disorders may be associated with inflammatory processes and IBD symptoms. A self-perpetuating cycle is therefore plausible, through which the fear of urgency or fecal incontinence can itself worsen symptoms of anorectal dysfunction.[33]

## Management of Urgency

It is crucial that urgency is explicitly addressed by gastroenterologists because of its high symptom burden and importance to patients in achieving treatment satisfaction. Urgency has been reported as the symptom that patients with UC would most want to see addressed, above that of rectal bleeding, abdominal pain, or diarrhea.[4] A Spanish study sought to explore what treatment priorities are considered the most important to patients with IBD, compared with those of gastroenterologists who treat IBD. Patients prioritized improvement in their quality of life and symptom control, particularly abdominal pain (23%) and bowel urgency (17%).[34] This priority was in contrast to that reported by gastroenterologists, who prioritized healing of mucosal lesions. Aligning physician and patient expectations is necessary to achieve shared responsibility for care and satisfaction. Nonetheless, the burden of urgency is underreported by patients in the clinic and unrecognized by physicians.

Urgency must be explicitly asked about in clinical care because patients may otherwise find it embarrassing or uncomfortable to self-report or volunteer this symptom.[9] That involves more than a binary yes/no question (such as, Do you have urgency?), and gentle and sensitive inquiry into the potential consequences of urgency is necessary (inquiry into the fear of urgency, whether a patient is always able to reach the bathroom in time, or whether he or she has had bowel-related accidents). Moreover, a view that urgency is an "accepted" burden of UC needs to be challenged.[35] For example, patients may adapt to urgency, and consider it a part of having UC, but not consider the failure to address this symptom as a failure

**Table.** Holistic Approach to the Management of Urgency in Ulcerative Colitis

| Treatment Consideration | Example(s) |
|---|---|
| Recognition of the presence and impact of urgency | Explicit, empathetic inquiry of patients about urgency and its consequences (eg, via the Urgency-Numeric Rating Scale) |
| Emotional support | Access to counseling, IBD specialist nurses, community continence advisory team |
| Social support | Dedicated social support networks and clinician liaison with employers/educational institutions to explain the problem and request understanding for the individual |
| Physical support | Appropriate investigation (flexible sigmoidoscopy, biopsy, anorectal physiology, imaging)<br>Medical management of urgency (reduce inflammation, anticholinergics to modify rectal hypersensitivity), supported by access to specialist community or hospital-based continence services[a]<br>Complementary medical therapy may have a role |
| Research into mechanisms of urgency | Determine molecular mechanisms of urgency, role of rectal compliance, neuroenteric communication, microbiome, among other areas |

[a]Requests need to be initiated by the IBD specialist (hospital services) or primary care (community services).

IBD, inflammatory bowel disease.

of their treatment.[36] Urgency may be persistent and disruptive, yet patients may report that they are satisfied that their medication is keeping their disease under control.[36] According to the UC Narrative, a global patient and physician survey of 2100 patients and 1254 physicians across 10 countries, two-thirds of physicians believe that over half of their patients think experiencing urgency is part of living with UC.[35]

In adopting a holistic approach to patient care, management of urgency should encompass the social and emotional disability that can result, with an emphasis on supporting patients in developing social support networks or in liaison with employers or educational institutions. This may be achieved, for example, through raising awareness of urgency in UC, arranging counseling support, or with the aid of specialist IBD nurses as part of a multidisciplinary team.[23] Management of urgency should also involve facilitating patient access to specialist continence services or protection tools.[5] Specialists in IBD frequently forget that there are community- or hospital-based continence services that may help patients with practical measures. Using such services is not a confession of failure of medical therapy, but integral to improving the quality of life of patients. When addressed, improvement in urgency appears to be 1 of the 3 most important contributing factors among patients who reported being satisfied with their medications, alongside reduced frequency of disease flares and abdominal pain.[35] A summary of approaches to the holistic care of urgency can be found in the Table.

Bowel urgency is not currently incorporated into most indices of clinical disease activity, but represents one of the components in the Simple Clinical Colitis Activity Index and the American College of Gastroenterology Activity Index.[28,37] New indices specifically to assess urgency have also been developed, including a single-item patient-reported outcome measure, the Urgency-Numeric Rating Scale (urgency-NRS).[2] The 11-point scale (0-10, from absence of urgency to worst ever experienced, where a change of 3 points is the minimum clinically relevant difference) was constructed to meet regulatory guidance on patient-reported outcome development and allows longitudinal collection of data. The urgency-NRS correlates moderately or highly with measures of health-related quality of life and patient reports of UC severity, as well as other UC symptoms such as stool frequency and rectal bleeding, yet has a low correlation with measures such as endoscopy or histopathology.[38] A failure to consider urgency and its consequences in clinical trials or care risks omitting a relevant clinical symptom and contributor to patient well-being.

## Conclusion

Bowel urgency is a common and debilitating symptom that places a substantial burden on the quality of life of patients. The high reported prevalence and impact of urgency on the employment, education, and socialization of patients demonstrates that the control of

urgency remains an area of unmet need. Its management necessitates a multidisciplinary approach, reflecting the complexity of its pathophysiologic drivers, with its varied emotional and behavioral impact. The explicit inquiry and discussion of urgency between patients and physicians in clinics will facilitate shared ownership of care and shared prioritization of treatment goals. Similarly, the incorporation of specific measures of urgency in research and clinical trial outcomes will help drive patient-centered, meaningful advancements in the understanding of UC and associated therapeutic developments.

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