



National differences in ulcerative colitis experience and management among patients from five European countries and Canada: An online survey



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Abstract

Background and aims: Patients' and physicians' perceptions of ulcerative colitis and its management are important for developing and guiding appropriate therapies. This study explored national differences in patients' and physicians' experiences, expectations, and beliefs about ulcerative colitis.

Methods: Structured, cross-sectional, online surveys evaluating various indices were completed by 775 adult patients with ulcerative colitis and 475 physicians actively managing ulcerative colitis patients from France, Germany, Ireland, Spain, the United Kingdom, and Canada.

Results: Patients' classification of their symptom severity differed across countries (mild, 16%–45%; moderate, 46%–58%; severe, 4%–36%). Expectations of disease control also varied, with 26% (Ireland) to 65% (Spain) describing that remission realistically involves “living without symptoms.” Within each country, more patients (45%–69%) than physicians (28%–45%) considered ulcerative colitis symptoms to affect patients' quality of life. Mean number of patient-reported flares during the past year ranged from 2.5 in Ireland to 8.0 in France. Self-reported adherence with oral 5-aminosalicylic acid (during remission) was highest in Spain (91% vs 50%–73% across other countries). Spanish patients were more likely to self-adjust their

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medications (54% vs 2%–5%), but reported the most dissatisfaction with therapy (42% vs 9%–27%). Irish patients were least likely to arrange physician/specialist nurse visits (14% vs 36%–49%) and least open to discussion of their condition.

Conclusions: Important national differences in ulcerative colitis patients' attitudes and perceptions were observed, which may help physicians improve patient care based on country-specific needs and influence self-assessments in clinical trials. The results suggest a need for structured patient education to improve adherence and outcomes.

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1. Introduction

Ulcerative colitis (UC) is an inflammatory bowel disease that typically runs a relapsing–remitting course.¹ Patients who develop this condition tend to experience a range of gastrointestinal and systemic symptoms, including bloody diarrhea, crampy abdominal pain, fecal urgency, tenesmus, loss of appetite, weight loss, and fatigue.² The course of the disease can vary from being well-controlled to having regular relapses; in the Norwegian IBSEN study, 55% of patients with UC reported remission or mild symptom severity after initial high activity in the previous decade, while the remaining patients reported either chronic intermittent or chronic continuous symptoms.³

The main objective of treatment in UC is the achievement and maintenance of disease remission, while also preventing the development of complications. Treatment for mild-to-moderate UC usually centers on 5-aminosalicylic acid (5-ASA), an anti-inflammatory compound available in a wide variety of oral and rectal formulations.^{4–6} For more severe disease, corticosteroids, immunosuppressants (thiopurines or calcineurin inhibitors), or anti-tumor necrosis factor agents may also be considered.

As reported previously in the US Ulcerative Colitis: New Observations on Remission, Management and Lifestyle (UC: NORMAL) survey, perceptions, beliefs, and issues that patients have regarding UC and its treatment can differ substantially from those of physicians.⁷ To investigate this further, we conducted an international survey of patients with UC and health care professionals involved in the care of UC patients to further explore the differing perspectives and perceptual gaps relating to UC and its management that exist among patients, physicians, and nurses.⁸ Here we report on national differences in patients' and physicians' experiences, expectations, and beliefs about UC and its management across 5 European countries and Canada. To our knowledge, this is the first published study to evaluate national differences in these outcomes.

2. Materials and methods

2.1. Respondents

Participating patients were aged ≥ 18 years and had a previous formal clinical diagnosis of UC (any severity). Patients who had undergone prior colectomy were excluded. Physicians who took part in the survey included gastroenterologists or internal medicine physicians with a specialist interest in gastrointestinal medicine. Although the survey

was also completed by nurse specialists, recruitment of nurses for this survey was based only in the United Kingdom and their results were excluded from the current analysis focusing on national differences. Although all physicians were involved in the management/treatment of patients with UC, they were not necessarily directly linked to the patients enrolled in this study. Physicians were excluded if: <50% of their working time was devoted to clinical care/practice; they worked in a consultative or advisory capacity to the pharmaceutical industry; they had qualified to practice within the last 3 years; or if they did not personally see patients with UC. All respondents provided their consent before completing the questionnaire and were remunerated by the sponsor for their participation. Participating physicians were paid £35 (EU countries) to £40 (Canada) each; participating patients were paid £70 each in France, Germany, Spain, and the United Kingdom, £75 each in Ireland, and £90 each in Canada.

2.2. Study design

This study was an Internet-based survey of patients with UC and physicians actively managing UC patients from Canada, France, Germany, the Republic of Ireland, Spain, or the United Kingdom. Respondents were pre-identified from patient and physician access panels and recruited via e-mail or custom "phone-to-Web" recruitment. In cases where e-mail addresses were included on the panel lists, e-mail invitations to participate in the survey were sent directly to respondents without any prior telephone or personal contact. In cases where the panel list only included telephone numbers, interviewers telephoned respondents to request their e-mail addresses and sent out e-mail invitations to them while they were still on the telephone. All e-mail invitations included a hyperlink to the applicable online questionnaire. As part of the recruitment process, respondents were carefully screened to ensure that they met the above eligibility criteria.

Patient advocacy groups and associations were not used for recruitment purposes in an attempt to avoid potential bias by over-sampling patients who were likely to be more aware of their condition and who were more actively engaged with UC management. Additionally, sampling was conducted as randomly as possible and with full geographical dispersal to try to achieve a broad and representative range of respondents in each country.

2.3. Survey tool

Respondents completed structured, cross-sectional, computer-aided, Internet-based questionnaires that assessed

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