

The



of Inflammatory Bowel Diseases (IBD)

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS (EFCCA)

Giving Patients with IBD a Voice

Patients often understand the impact of a chronic disease on their lives far more than clinicians. This is why their perspective on IBD was at the centre of the IMPACT study, a pan-European survey.

Inflammatory bowel diseases (IBD) such as Crohn's disease and ulcerative colitis are among the catalogue of maladies, which become lifelong nasty companions: chronic diseases. IBD are chronic inflammatory disorders of the gastrointestinal tract, affecting about three million people in Europe whose disease is never fully conquerable.

Patients experience periods when their disease flares up and causes symptoms, i.e. diarrhoea, rectal bleeding, abdominal cramps and pain, fever, loss of appetite, weight loss and fatigue, followed by periods of remission when patients may not notice symptoms at

the authors concluded that „the incidence rates of ulcerative colitis (UC) and Crohn's disease (CD) have continued to increase.”

⊕ The mean incidence rate for UC increased from 1995 to 2011 by 60 percent in women and by 70 percent in men.

⊕ For CD the rates increased during the same time by 30 percent in women and by 60 percent in men.

IBD have a detrimental impact on quality of life and the ability to work. A study in a large population-based cohort of patients with CD in Sweden shows that CD has an even

greater negative effect on quality of life than UC. This difference was pronounced for women.

EFCCA believes that patients understand the impact of their disease on their lives often far more than their clinician. This is why EFCCA launched the IMPACT survey to learn more about

the patients' perspective and the experience of their disease in different countries. What impact has IBD on their lives, on social relations, their education, their job and careers? How do patients experience the quality of healthcare as well as their access to healthcare and support facilities in different countries? The results shed light on aspects of the disease, which are of utmost importance for patients and their every day living but are not necessarily in the focus of research.



4600 patients spoke out in the first pan-European survey to call attention to their experience with IBD and it's impact on their lives

all. This is why IBD and their related symptoms are sometimes considered less „socially acceptable” adding an extra psychological strain on patients.

The incidence of IBD has increased during the 20th century in Western Europe and North America, IBD are diseases of modern societies. They are still on the rise as a recently published study shows. Based on data from the Danish National Patient Registry

A European Crohn's and Ulcerative Colitis Patient Life 2010 - 2011

THE IMPACT SURVEY

The IMPACT survey was a joint project of EFCCA and its national member associations. It was launched in November 2010 and closed in August 2011. IMPACT II is now on-going in several other countries in and outside Europe. The main aim of the survey was to obtain an international perspective of the impact of Inflammatory Bowel Disease (IBD) on patients' lives. Individual member organisations of EFCCA in various European countries were responsible for the launch and communication of the survey to their own members. This happened in different ways in different countries. In all countries it was a self-selection online-survey and participation was optional. It is therefore not to be considered a completely random survey though it provides relevant insights into the perspective and perceptions of patients with this disease in different countries.

4,670 online responses that had been received by the close of the survey were included in the analysis. The survey was supported by an unrestricted educational grant from Abbott.

The survey has received wide recognition from the scientific community and its poster presentation at the ECCO Congress in 2012 was awarded a „poster of distinction ribbon”. It was also recently published in the *Journal of Crohn's and Colitis*. (J Crohns Colitis. 2014 Mar 21. pii: S1873-9946(14)00102-0. doi: 10.1016/j.crohns.2014.03.005. [Epub ahead of print])



United We Stand

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INFLAMMATORY BOWEL DISEASE AND HEALTHCARE

Managing a Complex Disease

Advances in the understanding of IBD paved the way to new treatment concepts as well as to novel drugs. This also requires to improve communication between physicians and patients.

Patients with IBD have not only to conquer the emotional challenges of an incurable illness. Even when they are in remission and don't have to confront their disease, this can change from one day to another. Anytime something can happen to remind them that their disease is inescapable, their shadow: most patients will experience a relapsing and remitting course of their disease.

Somewhat shockingly, the IMPACT survey shows that 83 percent of the respondents at least once a week even between flares feeling tired, weak or worn-out. Some respondents report to have all symptoms between their flares.

Diagnosis may be delayed as the result of the many signs and symptoms of IBD. This is why EFCCA's IMPACT survey shows that only 54 percent of the respondents received a final diagnosis within a year from onset of symptoms, one third got diagnosed within the first six months. But notably 17 percent of the respondents had to wait more than five years. Generally younger people were not only diagnosed faster but also saw a specialist earlier than adults. In the first six months after onset of symptoms 40 percent of the younger people received the diagnosis and 63 percent met a specialist.

The management of IBD is changing: the introduction of so called biologics has improved treatment and treatment goals have

been changed and expanded to include healing of the lining of the intestine. More drugs to modulate the immune system are in development. „They will cause treatment approaches to evolve further”, as an expert states in the US-journal JAMA.

As the IMPACT survey shows, 5-aminosalicylates (ASA) are still the most commonly taken drugs, especially by patients with ulcerative colitis (UC). More than half of the respondents had taken corticosteroids and about one third were treated with immunosuppressives.

Latest US and European treatment guidelines recommend against use of 5-aminosalicylates to treat Crohn's disease. So biological drugs are on the rise at least in the treatment of this illness: The IMPACT survey shows that 36 percent of patients with Crohn's disease and 12 percent of patients with ulcerative colitis were treated with biologicals. About 56 percent of respondents were satisfied with their treatment plan.

The IMPACT survey shows that hospitalization is common. The majority of patients – 85 percent – had been hospitalized in the past five years. This applies especially to patients with CD of whom 89 percent had been in hospital.

FACTS AT A GLANCE

- ⊕ 54% of respondents had received a final diagnosis within a year from noticing first symptoms
- ⊕ 69% of respondents saw a specialist in the first year of their illness
- ⊕ 17% had to wait more than five years to receive a final diagnosis
- ⊕ 56% were satisfied with their treatment plan
- ⊕ 40% had been operated due to IBD
- ⊕ 73% of the patients who had been operated were satisfied with the outcome
- ⊕ 54% didn't get to tell the specialist something important at their appointment

Patients having frequent relapses of their disease despite optimal medical treatment have few options other than surgery. This is why not surprisingly 40 percent of IMPACT respondents had surgery due to IBD, two

In Poland you still do not have the same access to care for everyone, it all depends where you live. If you live in the countryside, away from an IBD care center, you might not get the adequate treatment on time or with a delay that might have serious consequences on your healthcare.

Marek Lichota, Poland

percent had even more than ten surgeries. The majority was satisfied with the surgery outcomes.

Communication with the physician can often be less satisfying for many patients and for patients with IBD as well. Most of the respondents of the survey felt that their gastroenterologist should have asked more probing questions to understand their disease status and 54 percent felt that they did not get to tell something important to their physician. 69 percent felt they had adequate access to their IBD professional and 65 percent reported that their gastroenterologist was best at giving them sufficient time at the consultation.



„When I was diagnosed, I wasn't explained very thoroughly what I was dealing with. I didn't really even understand it was a chronic illness. I've been treated by many doctors in the sixteen years that I've had Crohn's disease, and while some of them have been wonderful, with some I have felt like they are already pushing me out of the door when I still have questions to ask.”

Sanna Lönnfors, Finland