

# The IMPACT 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.

**I**nflammatory 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 YOUNG PEOPLE

# Life is Like a Constant Uphill Battle

Chronic inflammatory bowel diseases are on the rise. More worryingly is the growing incidence and aggressiveness of the diseases in childhood and adolescence.

**H**aving a chronic illness in school, college, university or training on-the-job is tough. For young people with IBD, balancing their life and their disease is a „constant uphill battle” as a patient puts it. Life is especially rough when the disease is in full swing. A flare-up can force students to leave university in the middle of the semester or knock down a trainee in the midst of an internship. The disease may disrupt education and gets in the way of young people’s ability to perform to full potential.

**The incidence of IBD in children** and young people increased in all Western countries over the past years. Crohn’s disease, once considered rare in young age, is currently recognized as one of the most important chronic diseases that affect children and adolescents. The patients often experience growth failure, malnutrition, pubertal delay, and bone demineralization. Approximately two out of ten patients with CD present when they are younger than 20 years. In Canada scientists report a significantly increasing incidence in children under ten years of age. They call this „a worrisome finding, and another important area of further research.” The variability of incidence and prevalence of IBD throughout Europe is quite high with a East-West gradient in incidence as a study of the European Crohn’s and Colitis Organisation (ECCO) shows. This might reflect different underly-

ing genetic susceptibilities as well as different environmental factors influencing the development of the disease. Whereas ulcerative colitis (UC) seems to peak between 10 and 18 years and affects both genders equally Crohn’s disease (CD) incidence seems to peak late in adolescence and in young adulthood up to 25 years of age and male predominance has been observed in the paediatric age under 16 years.

163 out of 4670 respondents participating in the IMPACT survey were 18 years old or younger. 65 percent had Crohn’s disease, 29 percent ulcerative colitis. This reflects latest epidemiological evidence from USA.

It is well established that children and young people with a chronic disease like IBD report lower health-related quality of life as compared to their healthy peers. Also an increased risk of psychosocial problems may encounter children and young people with IBD depending on the activity of the disease. Negative consequences in terms of psychosocial development are also prevalent as few studies show.

**This also applies** to the respondents under 18 years of the EFCCA IMPACT survey. The majority of them – 61 percent – felt that IBD had affected their ability to perform to their full potential in an educational setting. Also

## FACTS AT A GLANCE

- ⊕ **The majority of young patients felt that IBD affects their ability to perform**
- ⊕ **patients under the age of 18 are diagnosed faster when first symptoms occur. In the age between 19 and 34 diagnosis takes longer**
- ⊕ **The majority of young patients sees a specialist within the first year after first noticing symptoms and have better access to their specialist than older patients**
- ⊕ **Meeting other patients with IBD seems to have a more positive impact on young people**

more than half (57 percent) of the 19-34-year-olds felt this way.

**The good news can be found** in the answers of younger patients with respect to their medical care. Young people were generally diagnosed faster after first noticing symp-

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**„I felt very angry when I was diagnosed. IBD steals life of young people - people who have their whole life ahead of them and so many things to do. We need to make sure that youngsters are supported as much as possible especially during their years of education.”** *Tiphaine Chapeau, France*  
 .....

toms. 40 percent were diagnosed within six months, 66 percent within a year. In older age groups, diagnosis took longer. The majority of younger people were seen by a specialist within a year after the onset of first symptoms. 64 percent saw a specialist within six months, 82 percent within a year.

Eight out of ten in the younger age-group reported to have adequate access to their IBD professional. Young patients also have better access to psychologists or other counsellors: 36 percent of the under 18-year-olds reported to have a psychologist or counsellor at their IBD clinic whereas only ten percent of the 55-year-olds report this. This difference might reflect the well known reluctance of elderly patients with chronic diseases to accept and look for psychological support to cope with their ailments.



**„Young, sick and ready to fight: When I was diagnosed with UC a lot of questions went through my mind. What could I do to live my life in the best possible way? What goals did I want to achieve? Basically: Who should I be? Big questions, but when your health and life is put to extremes, you should start wondering about what you can do to help yourself in the best possible way. I wanted to prove that IBD wouldn’t influence my dreams and goals - in short: I wanted to retake the control of my own life.”** *Daniel Sundstein, Denmark*



it's hard to find a job when you have a chronic disease and it's a real moral dilemma to decide whether you should mention your disease or not when you apply for a job. I have had IBD for eleven years but I have been lucky and have found a very good employer.

*Aslaug Eva Bjornsdottir, Norway*

## INFLAMMATORY BOWEL DISEASE AND EMPLOYMENT

# Worrying about Health and Job

Inflammatory bowel diseases often hit people when they are at a peak time in their career. EFCCA's IMPACT survey and many other studies describe the precarious situation of these patients.

Juggling demands at work and feeling sick is never easy, but when you have a chronic illness like IBD colleagues can become annoyed and bosses impatient. Crohn's disease (CD) for example frequently presents for the first time during early adulthood, a peak time of work productivity. In view of this difficult situation it is not really surprising that many employees with chronic diseases face also a never ending chronic uncertainty and are forced to worry not only about their health but about their jobs as well. Above all some patients report that they had experienced more problems with colleagues and their boss than with their disease.

**You think you always have to compensate for your tiredness so you try to work harder than other people. You never know whether you should mentioned too much that you are sick as your employer might think twice whether they should hire you or not.** *Chayim Bell, the Netherlands*

„Patients who consistently report low quality of life, or have frequent flares requiring surgical intervention or hospitalization for medical management, may be at risk for CD-related work disability”, US-researchers conclude after studying characteristics that were associated with work disability of patients with CD.

**This holds true for younger people** and women in particular as a Canadian study shows. „Younger age, female gender, shorter disease

duration, and prior bowel resection predicted a higher likelihood of unemployment” the authors write in the Journal of Clinical Gastroenterology. Not surprisingly a study in USA shows that remission in patients with moderately-to-severely active CD is associated with improvement in employment.

**EFCCA's IMPACT survey confirms** and supports these findings: IBD has a tremendous impact on the working life. The majority of the 4670 respondents are between the ages of 19 and 44. This is the period in life when the course is set for education, professional development and career. In this phase people get settled in their job and

work hard to work their way up and climb the ladder. This is why so many of the respondents agree upon statements on drawbacks in their worklife. Almost a quarter of the respondents have experienced unfair reactions at work in relation to their disease. One out of five respondents – 20 percent – felt that they had been discriminated at work due to IBD and 56 percent stated that IBD had negatively affected their career.

Most respondents had had to take time off work in the last year due to IBD, a quarter even over 25 days, and in the IMPACT survey young respondents had had more sick days than older ones. Fatigue and too little energy were most common reasons. Unemployment and losing one's job is also a

## FACTS AT A GLANCE

③ 24% of respondents had received or heard unfair comments from superiors and/or colleagues about their performance at work in relation to their illness

③ 20% felt they had been discriminated at the workplace due to IBD

③ 56% of respondents agreed that IBD had affected their career path

③ 31% of respondents agreed or strongly agreed that they had lost or had to quit a job due to IBD.

③ 40% of respondents had made adjustments in their working life

③ Younger respondents tended to have had more sick days due to IBD compared to the older ones

consequence of the disease many patients have to experience. The portion of respondents who agree that they had lost or to quit their job due to IBD is high – 31 percent.

Only a smaller portion of patients responding to the survey – 28 percent – felt that their work performance was unaffected by IBD and one fifth felt that their disease had not negatively affected their career. Presumably these might be patients with milder forms of IBD.

Patients also describe the drawbacks of IBD for education. Almost half agreed or strongly agreed that IBD had negatively influenced their ability to perform to their full potential in an educational setting. This is not surprising with respect to the fatigue and feelings of low energy coming with IBD. According to researchers from Utrecht University, The Netherlands, fatigue in people with IBD is comparable to those suffering from cancer.

**Fatigue and feelings of exhaustion** are not confined to the acute episodes of IBD. This is one important finding of the IMPACT survey. It is in line with previous findings in other studies. Even in periods of remission when other symptoms of the disease disappear fatigue stays with all the adverse effects on the everyday life of the patients.

## 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.

**P**atients 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*