

What do patients with inflammatory bowel disease find important in their treatment?

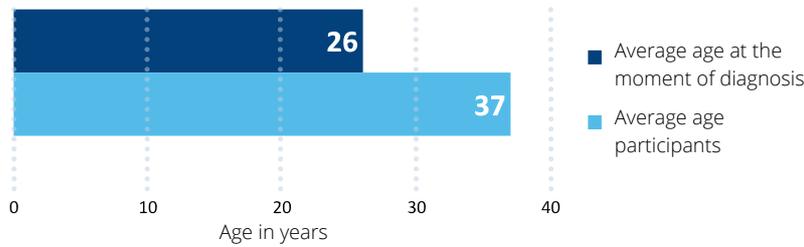
Why did we carry out this study?

Due to their disease, patients are experts by experience. Therefore they can provide insights on their treatment to inform drug development, approval and reimbursement. By conducting this study, we wanted to find out what patients with inflammatory bowel disease (IBD) find important in their treatment and why.

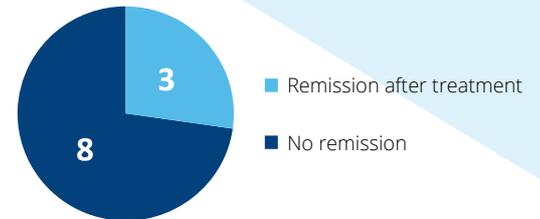
How was this study conducted?

Two group discussions with IBD patients were organised, where experiences were exchanged.

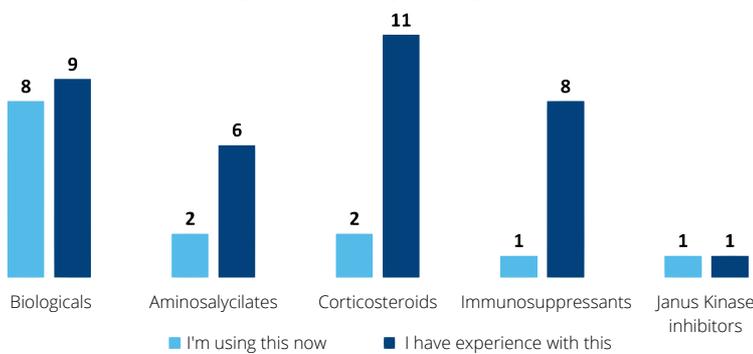
Who participated in this study?



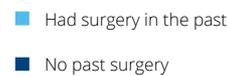
Disease activity



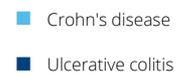
Treatment experience of participants (total = 11)



Surgery



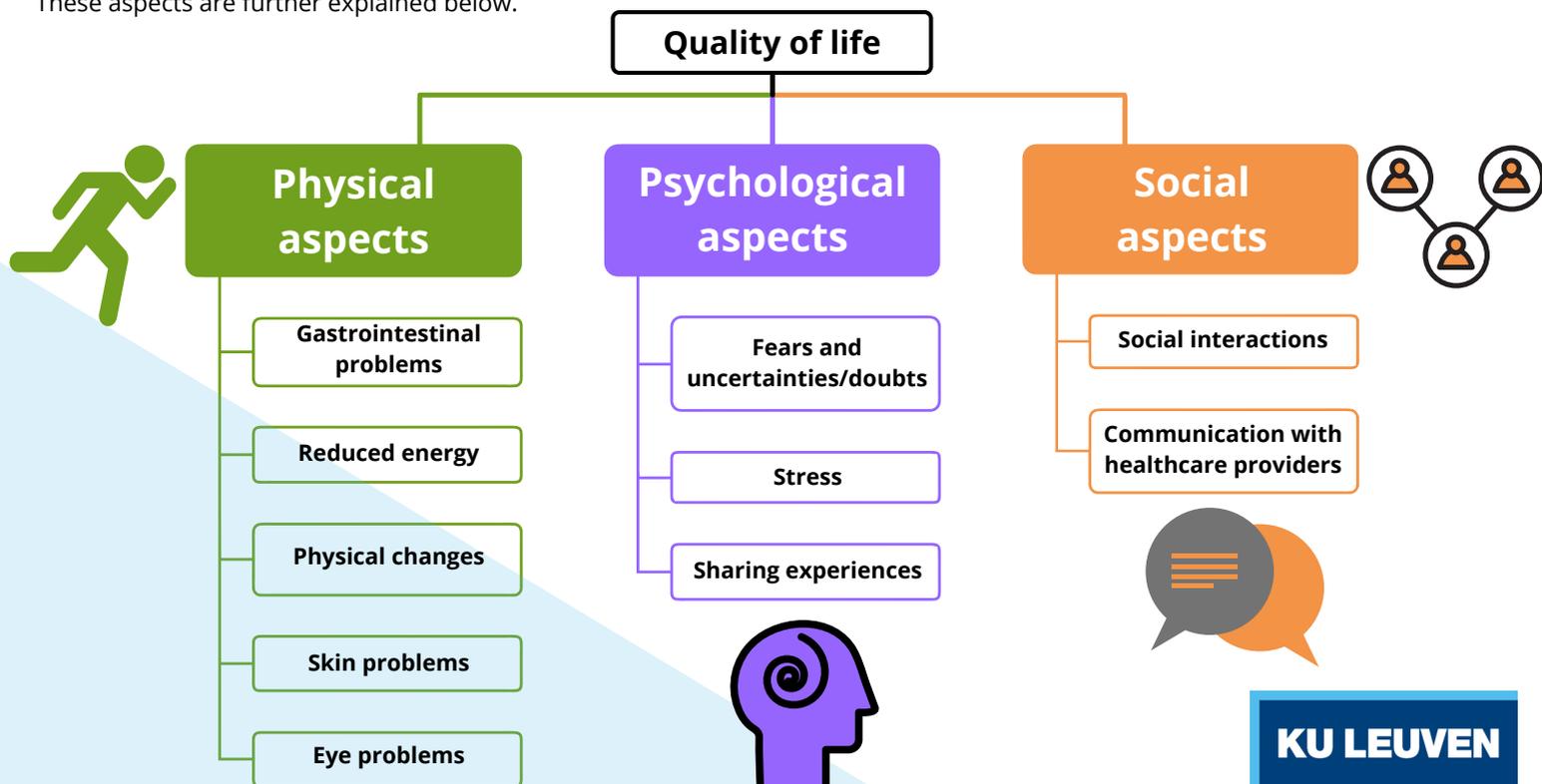
Diagnosis



What treatment features are important to IBD patients?

Patients want to be able to carry on with their lives as before the disease. The most important aspect for participants was therefore that medication could suppress their symptoms and their illness would remain stable; that the unpredictability of their symptoms would diminish and their daily lives would not be disturbed.

During the group discussions, the influence of **physical**, **psychological** and **social** aspects on patients' quality of life emerged. These aspects are further explained below.



Physical aspects

• Gastrointestinal problems

These problems contribute the most, due to the **physical discomfort, irregularity** and **unpredictability** of **sudden urges**. Therefore, gastrointestinal problems also have a major impact on both the psychological and social wellbeing of the participants.

• Reduced energy

Patients suddenly have to go to the toilet at night. This causes **sleep deprivation**, which has an impact on their work and social life. Medication can also cause chronic fatigue.

• Physical changes

The uncontrollable changes in **body weight and appearance** are bad for patients' self-esteem and often result from treatment with steroids.

• Skin problems

The importance of skin problems depend on the severity of this side effect. For example, acne is acceptable, but a serious rash is not.

• Eye problems

Patients are afraid of getting eye problems, as this can have a big impact on their lives.

Social aspects

• Social interactions

The lack of predictability of the disease prevents people from **making plans**. There is always a need for a toilet nearby. This makes it difficult to meet up with family and friends, or to go on holiday.

• Communication with healthcare providers

- Patients are generally **satisfied** with the communication between them and their healthcare providers, although it became clear that they often give **too little psychological support**. There is a feeling that the psychological impact of the disease is underestimated.
- Patients sooner want more **information** on the different treatment options, their impact, and short and long term side effects. They also want to be better informed on how to cope with the disease.



How will this information be used in the future?

The results will be used to draw up a questionnaire that we will send to IBD patients in different countries in Europe. In this way, we can mathematically determine how much importance patients attach to the characteristics discussed above. We will also investigate the unmet needs of IBD patients that cannot be solved with existing therapies.

Acknowledgements

We would like to thank all the patients who participated in this study.

For further questions, comments, or additional information, please contact:

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Psychological aspects



Patients often have **psychological problems** with their illness and/or their treatment. Several indicated that they needed psychological **support**.

• Fears and uncertainties/doubts

- There are concerns about the **efficacy** of medication. There is great uncertainty about whether a treatment will work or not, and **how long** it will work.
- The period between the start of a treatment and the occurrence of the desired effect varies greatly from patient to patient and between treatments. This uncertainty frustrates patients.
- Patients were concerned about the long term **side effects** of their treatment, and more specifically the increased risk of cancer.
- The need for **surgery** and the possible loss of an excessive amount of intestinal tissue is a concern, as it is not infinite and is necessary for proper food absorption.
- Patients are afraid of a **stoma**, fearing the **discomfort** and the **appearance**. One patient with a permanent stoma did share her positive experiences of living with a stoma.

• Stress

The negative impact of **stress** was discussed, and how it can cause abdominal cramps and sudden urges. Patients talked about the positive impact of sports and mental rest on reducing stress.

• Sharing experiences

Sharing experiences with fellow patients brings relief.

What to remember from the results?

- The most important aspect for patients in their treatment is that their symptoms are suppressed and they go into a long term remission.
- Patients want to avoid surgery and the need for a stoma.
- Patients want an improved quality of life. This means less frequent visits to the toilet and avoiding sudden urges. A reduced impact of their symptoms on work and social life is also essential.
- There is a need for more psychological support, also within the medical care pathway.