Patient perspective on the impact of complex perianal fistulas in Crohn's disease on quality of life: Introducing the concept of the patient survey conducted in Europe

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Background

• Perianal involvement in Crohn’s disease (CD), including fistulas, ulcers, abscesses, strictures and cancer, can lead to a significant, occasionally debilitating impairment in the patients’ short- and long-term quality of life (QoL).1

• Perianal fistulas can cause symptoms such as faecal incontinence, rectal pain, swelling and fever, which may significantly affect a patient’s social performance, sexual function and normal life activities.2,3

• Fistulas are a relatively common CD complication: approximately 35% of patients with CD have at ≥1 fistula and the majority of CD fistulas are complex.1,4,5

• Despite this, few studies have assessed the impact of complex perianal fistulas (CPF) on the QoL of patients with CD from the patient perspective.

Objective

• This survey aims to assess the impact of perianal fistulas in CD on patients’ QoL in Europe.

Methods

• A survey assessing the effect of CPF on the QoL of CD patients was developed by patient representatives and medical experts.

– It consisted of questions on patient demographics and questions relating to history and activity of CD with/without CPF, as well as the self-reported impact on QoL, including the impact and restrictions on close relationships and social life, sexual activity, professional life and absence from work (Fig. 1).

• The survey was launched online on the European Federation of Crohn’s & Ulcerative Colitis Associations’ (EFCCA) website on 15 July 2019 and remained open until 31 December 2019.

– The link to the survey was shared to national inflammatory bowel disease patient associations through the EFCCA network.

– Both CD patients with and without CPF were invited to participate in order to create a control group of patients for data analysis.

– The self-selective, anonymous survey was offered in English, French, German, Greek, Hebrew, Italian, Polish, Portuguese, Romanian, Spanish and Slovenian.

Results

• In total, 845 patients diagnosed with CD participated in the survey (Fig. 2) from 33 countries around the world (Fig. 3).

– 66.7% (n=564) patients were female.

– In addition to CD, 52.1% (n=440) of the respondents also suffered from ≥1 perianal fistula.

Conclusions

• The data collected will allow a comparison between CD patients with/without CPF, and between patients in different countries, in important patient-relevant aspects of QoL assessments.

• There are some limitations of the survey:

– Selection bias may have an impact on the data as the survey is self-selective, and only available online and in a limited number of languages.

– Recall bias may also have affected some responses due to the retrospective nature of a number of questions.

– The collected data will be statistically analysed thoroughly in 2020.

– Initial analysis of the survey responses showed that more than half of responders had ≥1 perianal fistula.

– The results will provide valuable insights and a deeper understanding of the often unspoken burden in the life of patients suffering from CD with CPF, and may potentially aid treatment decisions for these patients.

References


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Disclosures

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