



ORIGINAL ARTICLE

Patients' perceptions of surgery for inflammatory bowel disease

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Abstract

Aim: Surgery is indicated in selected patients with inflammatory bowel disease (IBD). However, due to a negative perception, surgery may be delayed, leading to possible unfavourable outcomes. The aim of this work was to investigate patients' perceptions of surgery and the impact on reported outcomes.

Method: An international multilingual online survey was used to query IBD patients' experiences of surgery, information sources, expectations and concerns, quality of life (QoL) and feelings.

Results: The survey was completed by 425 of 510 participants. Crohn's disease was more frequent (61%) than ulcerative colitis (36%). Most patients primarily learned about surgery from their gastroenterologist and were informed of the risks and benefits by the surgeon. In almost one-third of patients indication for surgery was not a shared decision

between gastroenterologist and surgeon. Seventy per cent of patients naïve to surgery were not aware of any surgical options. The majority of patients (80%) perceived surgery as the last option after many medical treatments rather than an alternative therapeutic option (20%). Sixteen per cent of patients obtained their primary information from the Internet, while 82.4% used the Internet to obtain additional information. Fear of surgical complications was cited by 73% of patients, while relief from symptoms was indicated by 31%. Most patients coped with their stoma better than expected or as they expected. Negative feelings decreased after surgery, while a lasting improvement in positive feelings and QoL was reported.

Conclusion: Despite the negative perception of surgery and the delayed involvement of surgeons as a source of information and in the decision-making process, the majority of respondents experienced positive outcomes from surgery, including improvement QoL and acceptance of the stoma.

KEYWORDS

feelings, patients, patients reported outcomes, perception of surgery, quality of life, stoma acceptance

INTRODUCTION

Common symptoms of inflammatory bowel disease (IBD) may impact the quality of life (QoL) of patients in both psychological and social domains [1–3]. Surgery has a pivotal role within the multidisciplinary team (MDT) in the treatment of IBD [4,5]. Indeed, surgery is a valid option at various stages, eliminating the target organ of ulcerative colitis (UC) and providing effective remission in Crohn's disease (CD), leading to a significant improvement in long-term QoL [6–10].

Despite the generally positive outcomes, the need for surgery itself represents one of the most common fears among IBD patients [11]. Patients with UC are reluctant to accept surgery, especially when it includes the possibility of a permanent stoma. Indeed, many patients would rather accept a risk of lymphoma or severe infection from medical therapy, regardless of drug efficacy [12]. Similarly, CD patients feel distressed when coping with surgery and often perceive it as a last resort due to failure of medical therapy [13]. This negative perception of surgery may trigger a negative loop that affects patients' willingness to undergo surgery; as a consequence, delayed surgery may lead to increased postoperative complications and impaired postoperative recovery [14,15].

The mismatch between surgical prejudice and reasonable outcomes deserves an in-depth analysis [16–18]. It is crucial to understand patients' subjective experiences and perceptions, of both those who have undergone and those who may undergo surgery, as these may shape their behaviour. This information is important in providing adequate counselling and empowering patients in the decision-making process. Despite its high clinical relevance, there is a shortage of studies investigating the experience of IBD patients in relation to surgery.

The present study aims to investigate the subjective perception of surgery in IBD patients.

What does this paper add to the literature?

Patients with inflammatory bowel disease have a negative perception of surgery, although the majority of them experience positive outcomes. Delayed involvement of the surgeon as a source of information and in the decision-making process may affect patient perception and lead to patients accessing misleading information.

METHOD

An international online survey (Appendix S1 in the Supporting Information) was created to explore IBD patients' perceptions of surgery. The survey was available in English, Italian, French, German and Dutch. Participants were invited by the European Federation of Crohn's & Ulcerative Colitis Associations (EFFCA) and national IBD patients' associations to complete the survey. The link to the survey website was also distributed through newsletters for patients with IBD, surgeons, gastroenterologists and other caregivers. Patients who had prior surgery and those who had not were all invited to join the study.

The survey explored individuals' perceptions of surgery, including information, expectations from surgery (postoperative complications, function and thoughts about a stoma), QoL after surgery, feelings before and after surgery and overall concerns, including psychological and social impacts. The survey was created with the Qualtrics suite (Qualtrics). The estimated time required to complete the survey was 30 min. Only the answers of responders who completed the entire questionnaire were included in the analysis. Participants' informed consent was obtained before accessing the



survey questions. The survey was available online from February 2019 to January 2020.

Statistics

Categorical variables are presented as their frequency occurrence and overall percentage. They were compared using the chi-square test or Fisher's exact test, as appropriate. Continuous variables are presented as mean (\pm standard deviation) or median (range) according to their distribution. All reported *p*-values are two-tailed, and *p*-values of less than 0.05 were considered statistically significant. Statistical analysis was performed using IBM SPSS Statistics for Windows, version 25.0 (IBM Corp.).

RESULTS

Demographics of responders

The survey attracted 510 self-registered participants from 39 countries. The questionnaire was completed by 425 of these (83.33%). The most widely used language was English (57%), followed by Italian (25%) and German (13%). The majority of respondents were female (68%), with an average age of 38 ± 12 years. CD was the most frequent diagnosis (61%), followed by UC (36%) and other IBD diagnoses (3%).

Surgical information

Overall, 300 (71%) patients had previously undergone surgery, while 121 (29%) had had no prior surgery. Respondents who had surgery were significantly older than patients who had not (39 ± 11.75 years vs. 33 ± 11.57 years, $p < 0.001$), yet there was no difference in age at diagnosis of IBD (25 ± 11.13 years vs. 25 ± 10.88 years, $p = 0.97$).

The majority of patients who had not undergone surgery (89/121, 67%) were not aware of a surgical option for their disease. Conversely, a minority of patients (25/121, 21%) reported no interest in surgery, despite having received a suggestion from their gastroenterologist to consider surgical intervention. Only 15/121 (12.5%) participants were scheduled to undergo surgery at the time of the survey.

Among the patients who had surgery, the time interval between IBD diagnosis and when surgery was proposed for the first time ranged from 0 to 480 months (mean 85 ± 197 months). Most patients reported that they knew about surgery as a treatment option mainly from a gastroenterologist (63%), sometimes through the Internet (12%) and less frequently from a surgeon (10%). When surgery was specifically offered as a treatment option, it was initially suggested by a gastroenterologist (73%) and less frequently by a surgeon (17%). Patients were informed about the potential risks and benefits of surgery either by a surgeon (62%) or by a gastroenterologist (61%) (Figure 1). Sixteen per cent of respondents obtained their

primary information about surgery from the Internet. In most situations, the decision to advise surgery was a shared decision between surgeon and gastroenterologist (76.2%).

Additional sources of information on surgery besides healthcare professionals

Approximately two-thirds of the patients (69%) searched for additional information on the Internet (82%). Only a minority of patients obtained information directly from other patients (10%).

Patients' fears and positive expectations

The majority of patients (80%) perceived surgery as the last option after many medical treatments rather than an alternative therapeutic option (20%). In general, the indication for surgery was perceived as negative: on a scale from 1 (very positive perception), to 7 (very negative perception); the mean score was 4.51 ± 1.78 . The most reported negative fears were surgical complications (73%), incontinence after surgery (51%), the need for a stoma (50%), developing short bowel syndrome (40%) and change in body image (37%) (Table 1). Conversely, the most frequently reported positive expectations were symptom relief (30.8%), prolonged well-being (16%) and reduced pain or complete elimination of pain (15%) (Table 1).

Surgery was a planned procedure in 67% of the patients, while it was an emergency procedure for 33%. Of those operated on, 58% of patients experienced postoperative complications while 58% reported a recurrence of clinical symptoms after an average of 4 ± 7 years (range 0–48 years). Most of the participants (83%) did not require reoperation, and the majority of patients (57%) did not require postoperative medical treatment.

Feelings before and after surgery

Among those who were operated on, the feelings just before surgery were described as 'afraid' (57%), 'depressed' (23%), 'impatient' (14%) and 'ambivalent' (8%), but also 'hopeful' (41%) (Figure 2). Immediately after surgery, patients reported a decrease in all the negative feelings and a stable increase in positive sentiments, which lasted for 2 months after surgery. The feelings of 'relief' (32%), 'comfortable' (22%) and 'happiness' (26%) had the biggest increase compared with presurgery status. Positive feelings were also highly reported at the time of the survey, when the patients were asked to recall their past surgical experience (Figure 2).

The need for social and family support

About half of the participants (53%) spoke with someone who had undergone the same intervention. The vast majority of patients

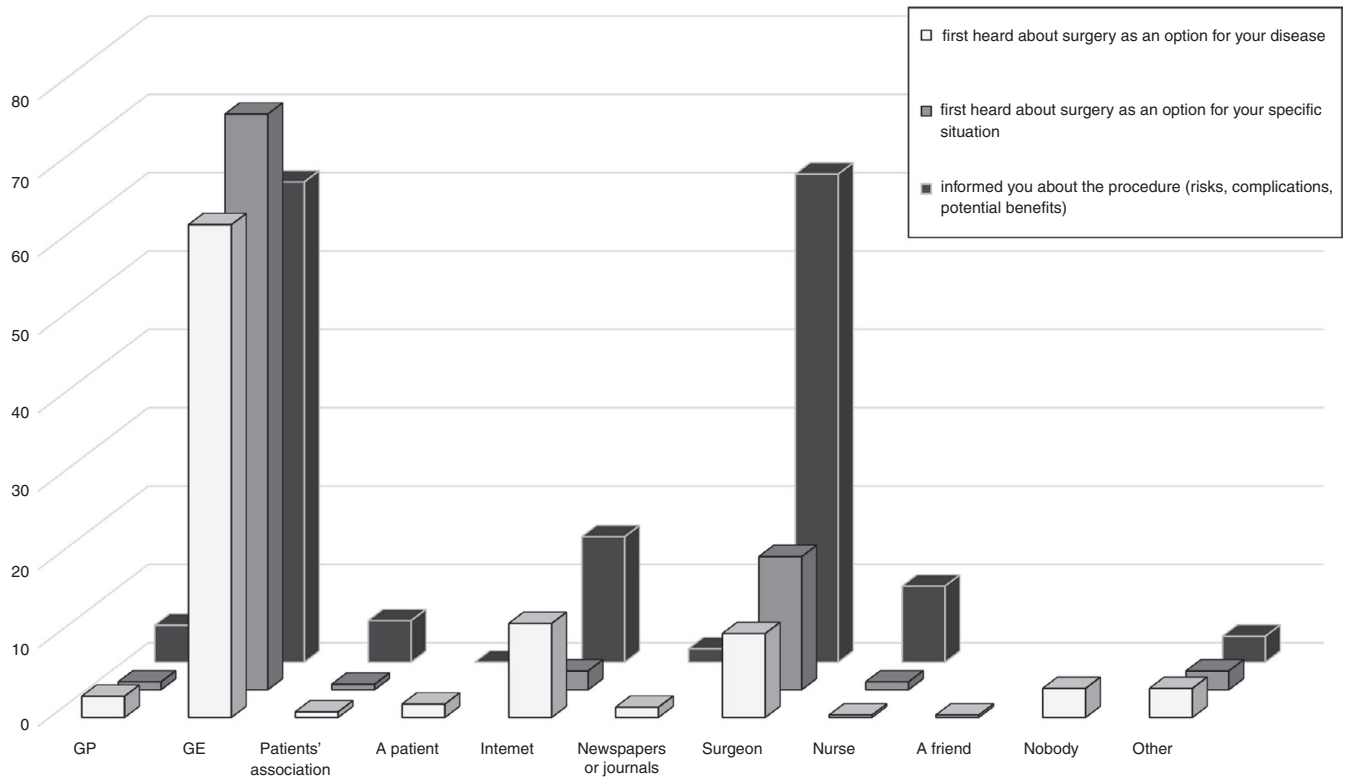


FIGURE 1 Sources of information about surgery

(78%) reported the need for social or family support, either for a short (46%) or a long (32%) period. Almost all participants (98%) felt supported by their families and from the social environment (80%).

Perception of the timing of surgery

About a third (35%) of the patients regretted that surgery had not been proposed earlier and 14% had thought of having surgery before receiving the suggestion from their gastroenterologist. Most patients reported that the timing proposed for the intervention was correct (55.4%), while a third declared that it was too late (37%), with only a limited number of patients (8%) responding that it was too early. The duration of the medical treatment was considered too long by 31%.

Experiences with a stoma

Only half of the surveyed patients (52%) received information about the possible creation of a stoma before surgery and 64% believed that they had been properly advised on possible complications. This information was considered accurate by most of the patients (68%), while some thought that potential problems were underestimated (29%) by their physicians, and only a few participants believed that these were overestimated (3%).

The main concerns regarding a stoma were the fear that it could be permanent (38%), followed by the fear of leakage (29%), cosmesis (12.2%) and foul odour (4%).

Most patients did not have a stoma (63%); less than a fifth of the patients (19%) had a stoma at the time of the survey and about the same proportion (18%) had undergone a stoma in the past. For most of them, the stoma was temporary (73%). Among those who had a stoma, living with the stoma was better than expected for the majority of the participants (69%), while only a minority reported that living with the stoma was worse than expected (13%).

The perception of having a temporary stoma varied among those who experienced it. However, an overall acceptance of a possible stoma was reported by 86% of respondents (Figure 3). Among these patients, 35% reported that they would prefer to avoid it but would accept it if needed, while 31% were strongly averse to it but would accept it if needed and 20% believed that it could be useful in some situations. Only 9% were strongly against a stoma and indicated they would not accept having one.

When comparing perceptions of life before and after having a stoma, respondents reported a significant decrease in social ($p < 0.001$) and professional ($p = 0.002$) aspects of their lives, but no differences were found when comparing sexual activity and sports before and after the stoma (Figure 4).

Quality of life after surgery

Following surgery, respondents reported an improvement in their physical well-being, but also in their psychological well-being and in activities of everyday life (Figure 5). Overall, the average quality

TABLE 1 Specific concerns and positive expectations related to surgery

	Responders, n (%)
Concerns	
Surgical complications	255 (72.6)
Having problem with continence after surgery	178 (50.7)
Stoma	175 (49.9)
Short bowel syndrome	140 (39.9)
Change of body image	131 (37.3)
Death	104 (29.6)
Cosmetic issues after surgery	93 (26.5)
The effect of your medications on the results of the surgery	58 (16.5)
Transfusions	27 (7.7)
Other	20 (5.7)
None	13 (3.7)
Positive expectations	
Symptoms relief	108 (30.8)
Prolonged well-being	55 (15.7)
Reduced or no more pain	51 (14.5)
No more drugs	26 (7.4)
Fewer drugs	19 (5.4)
Social life restoring	19 (5.4)
Greater life expectancy	15 (4.3)
More opportunities for leisure activities	7 (2.0)
Reduced or no more anxiety	7 (2.0)
Reduced or no more depressed mood	5 (1.4)
Better sexual life	4 (1.1)
Other	35 (10.0)

of life among responders was ranked good at 6.76 (SD = 1.96) on a scale from 1 (very bad) to 10 (excellent), whereas limited depressive feelings were noted (4.74, SD = 2.57) on a scale from 1 (not depressed at all) to 10 (very depressed), and this was coupled with anxiety (5.47, SD = 2.55), on a scale from 1 (not anxious at all) to 10 (very anxious).

Overall, the quality of life of those who had surgery was significantly higher than in those who did not have surgery ($p < 0.001$). No significant differences were found in the levels of anxiety or depression.

DISCUSSION

This international survey on the perception of surgery for IBD patients highlighted clinically relevant aspects which have not yet been extensively explored. The survey allowed a better understanding of the fears and concerns related to patients' perceptions of surgery. Additionally, it addressed the unique perspective of patients who

have had surgery compared with those who have not, and their respective outlooks.

Most of the time IBD patients had a negative perception of surgery, despite a favourable outcome for the majority of the patients which eventually matched the positive expectations of patients prior to embarking on surgery. In fact, QoL clearly improved after surgery, in line with a recently published randomized study comparing early surgery with intensified medical management [19].

The picture which emerges shows that the surgeon is not often involved in the decision-making process or as an information-provider.

To date, few studies have addressed the perception of surgery among IBD patients at institutional or (occasionally) national levels [13,20–23]. The present survey investigated a large international target population and provides a real-world picture beyond referral centres or a specific national health system.

In our study, about 30% of patients had not undergone surgery. Surprisingly, 70% of the surveyed patients who were naïve to surgery were not even aware of surgery as a possible option for their disease, while 21% reported a lack of interest despite recommendations from their physician. These findings confirm a well-known general lack of patient knowledge and are consistent with previous studies showing poor disease awareness [18,24,25]. On one hand, limited knowledge may be related to inadequate physician performance when addressing the needs of IBD patients, with a lack of adherence to the guidelines [26–29]. On the other hand, as reported by a recent qualitative survey, some IBD patients claimed they did not need additional medical information as they already felt secure and trusted their physician. Furthermore, some believed that additional information may be frightening and have a detrimental effect on their psychological well-being [24]. As a result, a mismatch in communication may be triggered by both patient and physician.

The majority of patients had already undergone surgery at the time of the survey, and had primarily received general information about surgery and tailored advice for their specific situation from their gastroenterologist. The involvement of the surgeon in an early phase with counselling patients about surgical alternatives was very limited and only occurred when specific information on surgical risks and benefits was requested. Importantly, indication for surgery was not a shared decision between gastroenterologist and surgeon in one-third of patients. Most guidelines advise that correct practice is to involve the surgeon at an early stage of the decision-making process [19,30–32]. Additionally, according to a previous study on preoperative counselling of IBD patients, patients themselves prefer to have an earlier consultation and discuss a surgical option with a surgeon rather than a gastroenterologist [20].

The percentage of patients collecting primary (up to 16%) and additional (82%) information on surgery from the Internet is compelling. This very common practice eventually carries a high risk of misinformation. In fact, patient-oriented websites on surgery for CD and UC (e.g. the first 100 websites found by the two most popular search engines) have been rated very poor in terms of reliability using the DISCERN criteria (in 88% and 98% of cases, respectively) [33,34].

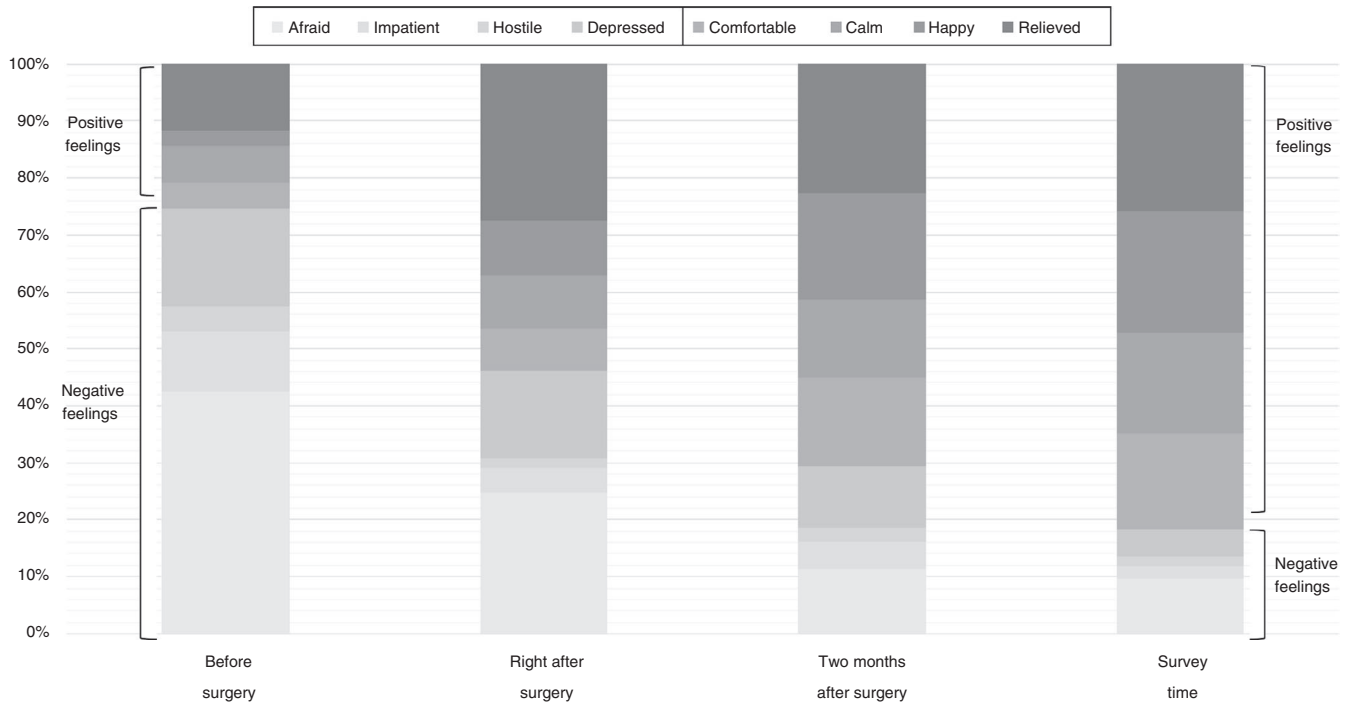


FIGURE 2 Patients' predominant feelings before and after surgery

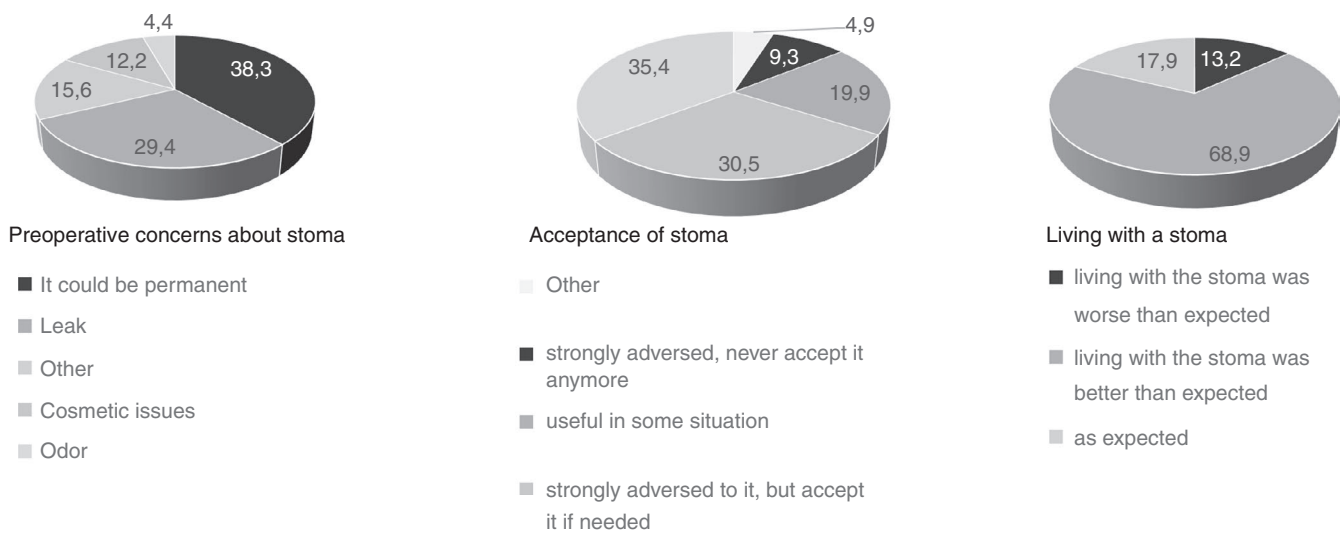


FIGURE 3 Preoperative concerns and postoperative acceptance of stoma

The specific fears of patients associated with surgery were mostly related to surgical complications (70%), which are reasonable preoperative concerns. These concerns are in contrast with the postoperative course reported by the majority of participants (83%), who did not experience major complications or reintervention during the same hospital admission. Although we do not have clinical data for the patients surveyed, the reported patient outcomes were much better than the preoperative concerns, suggesting a possible lack of preoperative counselling and overstated fears.

When considering patients' feelings before and after surgery, negative emotions (being afraid, impatient, hostile and depressed) clearly improved, while positive emotions (being comfortable,

calm, happy and relieved) increased and remained stably high over time.

Perceptions around the timing of surgery, which were measured postoperatively, revealed dichotomous thoughts related to preoperative fears and concerns that may have actually delayed a balanced decision to undergo surgery. In fact, many patients believed that surgery was delayed for too long and, conversely, that medical treatment was continued for longer than was necessary. A third of patients regretted that surgery was not proposed earlier. These findings are consistent with previous studies on QoL after restorative proctocolectomy (RP). Patients undergoing RP have reported high satisfaction after surgery and regretted not undergoing surgery

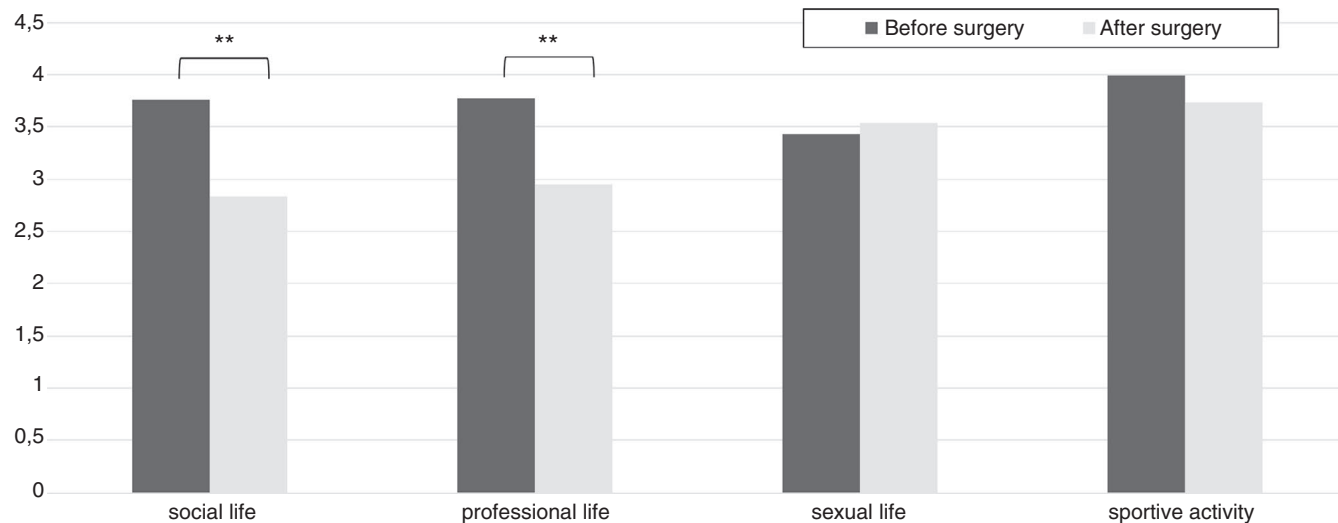


FIGURE 4 Quality of life before and after surgery

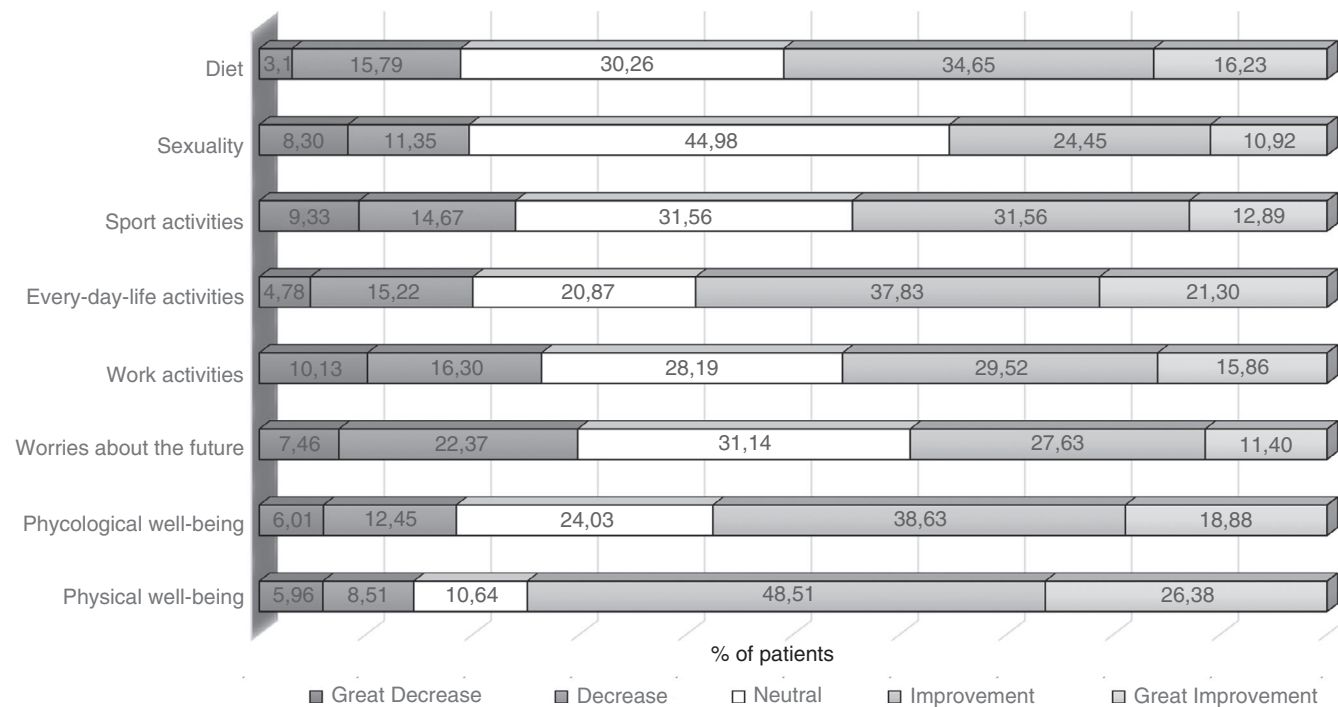


FIGURE 5 Impact of surgery on quality of life

earlier [35,36]. This concept holds true in CD, as reported in the randomized LIRIC trial comparing surgery with intensified medical treatment, as well as other studies [19,20].

The postoperative opinion of responders regarding stoma construction highlights further misperceptions and a need for more counselling. On the one hand fear of having a stoma was reported by 50% of responders as a specific preoperative concern. Although the stoma was mostly temporary (70%), for those responders who had one (nearly 40% of the responders) living with the stoma felt better than expected. Additionally, 86% of responders who had a stoma would accept it again if necessary. These results are consistent with the existing literature, as concerns and fears about stomas

are common in IBD patients [37,38]. Importantly, a high stoma acceptance rate has been reported in association with patient compliance and good interpersonal relationships [39].

Having a stoma is clearly associated with a decreased QoL, in particular for aspects related to social and personal life. This is in agreement with a recent meta-analysis that reported a high impact of stoma-related problems on the QoL of the minority of patients who are long-term ostomates with stoma complications [40]. The most prominent positive expectations reported by the responders were symptom relief, prolonged well-being and reduced pain, which translated into improved postoperative QoL when compared with preoperative status.

This study has its limitations. The study's sample consisted of self-selected patients who were willing to participate and were interested in contributing to the study's goals. Moreover, only those who completed the survey in full were included in the analysis. This issue could have biased the results of our study. Additionally, we are not able to tell whether the experience of self-selected-patients might represent a reliable sample of the IBD population. Our self-selected cohort retains similarities, in terms of demographics, with the latest epidemiological studies on IBD [41–43]. The similarities include the distribution of gender-specific prevalence, age-specific prevalence and the rate of surgery among the IBD population. Although respondents were evenly distributed throughout the various countries, the healthcare systems and culture may differ. Lastly, IBD patients were addressed as a whole, and the possible differences in perceptions between CD and UC patients were not taken into account. For instance, surgery is essentially curative for UC, and UC patients bear a higher cancer risk than CD patients. Additionally, patients' recall bias with regard to surgical information might be considered as a limitation to this study, along with the fact that no information on actual disease stage (mild or severe form) and type of medication was gathered.

The results of this survey may help to fill a gap in perception between patients' and clinicians' perspectives. In fact, healthcare providers could step up and offer improved interdisciplinary counselling earlier in the course of IBD so as to inform the patient and allow for shared decision-making, not only between gastroenterologists and surgeons but also together with an empowered patient. Ultimately, a well-informed patient will be more likely to follow the advice of an IBD MDT, including surgical options, which in turn could allow for a less stressful disease course. Patient information and education are crucial when managing IBD patients and optimizing patient-reported outcomes. Empowering patients by engaging them with timely and practical information is key to improving coping strategies, treatment outcomes and QoL, and thereby achieving a reduction in healthcare costs [18].

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CONFLICTS OF INTEREST

AS has acted as speaker/consultant for Johnson & Johnson and Takeda. MC has acted as speaker for Pfizer. SD has acted as consultant for AbbVie, Allergan, Amgen, AstraZeneca, Athos Therapeutics, Biogen, Boehringer Ingelheim, Celgene, Celltrion, Ely Lilly, Entera, Ferring Pharmaceuticals Inc., Gilead, Hospira, Inotrem, Janssen, Johnson & Johnson, MSD, Mundipharma, Mylan, Pfizer, Roche, Sandoz, Sublimity Therapeutics, Takeda, TiGenix, UCB Inc. and Vifor, and speaker for Abbvie, Amgen, Ferring Pharmaceuticals Inc., Gilead, Janssen, Mylan, Pfizer and Takeda. LA has acted as speaker/consultant for Abbvie, Amgen, Atlantic Health Care, Celgene, Celltrion,

Ferring Pharmaceutical, Janssen, Merck-MSD, Mundipharma, Otsuka, Pfizer, Shields, Shire, Tigenix, Takeda and Vifor Pharma. MA, HT, WB, LP-B, FP and JW have nothing to disclose.

AUTHOR CONTRIBUTIONS

AS and FP conceived the study. FP MC and AS analysed and interpreted the data. MC, AS, FP and MA drafted the manuscript. YP, JW, LP-B, SD, HT, WAB, LA, AdH, LL and PGK critically reviewed the manuscript. All authors critically reviewed and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICAL STATEMENT

Informed consent was obtained from all individual participants involved in the study.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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