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RESEARCH ARTICLE



Factors influencing patient preference for surgical treatment of ulcerative colitis: a single-center survey-based study

[Facteurs influençant les préférences des patients pour le traitement chirurgical de la colite ulcéreuse : une enquête monocentrique]

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Article received: 14 December 2021

First response: 15 December 2021

Article accepted: 22 March 2022

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Abstract: Ulcerative colitis is a primarily medically treated autoimmune disease. Patients not responding to medical treatment might require surgery and are generally presented with the choice of two procedures: ileal pouchanal anastomosis or an end ileostomy. The aim of this study was to describe the factors potentially influencing patients' preference for surgical treatment of ulcerative colitis. A single-center survey study was conducted. Eligible patients were sent an informative video about both procedures and were asked to respond to an online survey including colitis severity and its impact on quality of life (SIBDQ and SCCAI scores), demographic factors, a comprehension questionnaire, and their theoretical procedure of choice. Of 231 eligible patients, 68 completed the survey: 38 patients chose end ileostomy, 29 chose ileal pouch-anal anastomosis and one chose none. Females and patients that had their last symptomatic episode further in the past were more likely to choose end ileostomy. No other demographic factors were found to influence choice. SCCAI, SIBDQ or comprehension scores did not seem to influence choice. Having a stoma (76%), having to empty a stoma bag (72%), and problems with the stoma (38%) were the most significant factors for patients when choosing an ileal pouch-anal anastomosis. Several factors were cited by patients choosing end ileostomy, such as fecal incontinence (53%), frequency of stools (42%), and risk of pouchitis (42%). In conclusion, apart from female gender and time since last symptomatic episode, no factors related to colitis severity or demographics seemed to have influenced patients' choice. However, the wide distribution in the significant elements for patients when having to choose between IPAA and end ileostomy demonstrates the importance of a detailed information session.

Keywords: Ulcerative colitis; Inflammatory bowel disease; Proctocolectomy; Anal pouch; End ileostomy.

Résumé : La colite ulcéreuse est une maladie auto-immune généralement traitée médicalement. Les patients qui ne répondent pas ou ne tolèrent pas le traitement médical peuvent nécessiter une chirurgie et ont généralement le choix de deux procédures : un réservoir iléo-anal ou une iléostomie terminale. L'objectif de cette étude était d'identifier les facteurs influençant le choix des patients entre un réservoir iléo-anal et une iléostomie terminale. Une étude monocentrique de type sondage a été effectuée. Les patients éligibles ont dû regarder une vidéo informative sur les deux procédures et ont ensuite rempli un sondage en ligne portant sur leur information démographique, la sévérité de leur maladie (SCCAI) et l'impact sur leur qualité de vie (SIBDQ), ainsi que leur compréhension des procédures et leur choix théorique de procédure. Sur les 231 patients éligibles, 68 ont complété le sondage : 38 patients ont choisi l'iléostomie terminale, 29 le réservoir iléo-anal et 1 aucune chirurgie. Les femmes ainsi que les patients en rémission depuis plus longtemps étaient plus susceptibles de choisir l'iléostomie terminale. Le score SCCAI, le SIBDQ et le score de compréhension n'ont pas montré d'impact sur le choix. Les facteurs les plus importants pour les patients lors du choix d'un réservoir iléo-anal étaient le fait d'avoir une stomie (76%), de devoir vider le sac à stomie (72%) et les complications reliées aux stomies (38%). Plusieurs facteurs ont été cités par les patients choisissant une iléostomie, tels que le risque d'incontinence fécale (53%), la fréquence des selles (42%) et le risque de pouchite (42%). En conclusion, outre le sexe et le temps depuis les derniers symptômes, aucun autre facteur démographique ou associé à la sévérité de la maladie ne semblait influencer le choix de procédure. Toutefois, la grande distribution dans les éléments importants pour les patients lors du choix de procédure chirurgicale démontre l'importance d'une rencontre d'information détaillée pour choisir une procédure chirurgicale.

Mots clés : Colite ulcéreuse; Maladie inflammatoire de l'intestin; Proctocolectomie; Réservoir iléo-anal; Iléostomie terminale.

Introduction

Ulcerative colitis (UC) is an autoimmune inflammatory disease of the colon. It is characterized by recurrent isolated mucosal inflammation. It typically involves the rectum but may extend to the entire length of the colon [1, 2].

Patients with UC typically present symptoms of colitis, including but not limited to diarrhea with or without blood, colicky abdominal pain, urgency of defecation, tenesmus, and fecal incontinence. The severity of symptoms might vary from mild to severe, possibly leading to acute complications such as megacolon or perforation. UC is primarily treated medically to induce and maintain remission [3, 4]. Surgical treatment might become necessary for refractory disease or in the event of acute complications [5]. Two main procedures are available: proctocolectomy with end ileostomy or ileal pouch-anal anastomosis (IPAA); each has its particular complications. Neither is superior; both remain acceptable choices for patients in terms of complications and health-related quality of life (HRQOL) [6, 7].

Recent literature explored patient perspectives different medical on treatments to optimize treatment strategies, reduce adverse effects [8], and improve adherence to treatment [9]. A Danish study explored patient preferences and expectations for advanced treatments [10]. A review of numerous studies on patient preference for treatment options of inflammatory bowel disease compared different medical treatments with surgery [11]. While interest in studying patient preference is increasing, there is still a need for improving communication of treatment

options [12]. Patient preference for medical and surgical treatment options has been studied, but the detailed reasons for a patient to decide between different procedures were not assessed [13, 14]. Once considering surgery for the treatment of UC, the patient must choose between different procedures. Knowledge of complications related to different surgical alternatives is useful for health practitioners to guide patients with their choice for a surgical procedure, but the literature lacks the perspective of patients related to these complications.

Baker et al. [15] explored this subject by conducting interviews with 16 patients and concluded that the preoperative information did not address patient information needs. The same group conducted a study to develop and evaluate a patient decision aid for patients considering surgery and concluded that the DISCUSS study may eventually help clinicians and patients choose between IPAA or end ileostomy [16].

Given the literature, it is still unclear what motivates patients to choose one procedure over the other. Knowing the factors influencing patients' decisions could help clinicians in providing insightful information for patient-informed decision-making.

Objective

The main objective was to determine the factors influencing patient preference for their theoretical surgical procedure of choice (IPAA or end ileostomy) in a single-center UC population.

Methods

Study population and data collection

A survey-based study was designed to answer the research question. The study was

approved by the local ethics committee (authorization number 2017-1085).

Potential respondents were first identified from a list of patients registered with the inflammatory bowel disease clinic at the Centre Hospitalier Universitaire de Sherbrooke. Patients were mailed a reverse consent form. If they did not opt out, they were contacted by phone by the study coordinator and were given additional information about the study. The conversation was not registered and consent was obtained verbally. Eligibility criteria were then verified by chart review and questionnaires were sent by email to eligible patients. Patients had the option of coming to the research center to complete the questionnaires if they so wished.

Eligibility criteria

To be eligible for the study, patients had to be between 18 and 65 years of age, have a diagnosis of ulcerative colitis, and be treated by a gastroenterologist or surgeon at our institution. Patients with Crohn's disease and those who had already had an operation for UC were excluded. For patients over 65, comorbidity, poor sphincter tone and fecal incontinence could lead the surgeon to strongly recommend end ileostomy. For these reasons, we preferred to limit the study to patients who would have had the choice between the two procedures [17].

Survey design and administration

Eligible patients were first invited to watch an instructional video (enclosed in the email) about end ileostomy, IPAA, and their respective complications. It included a description of common complications and was created according to the Dubois et al. systematic review [18] of outcomes after IPAA and end ileostomy. The survey consisted of five parts: the Simple Clinical Colitis Activity Index (SCCAI) [19]; the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) [20]; demographic information; a comprehension questionnaire; and a surgery preference questionnaire allowing the patients to indicate the factors most relevant to them. The patients were sent a link to a LimeSurvey questionnaire by email. They

were given up to three reminders to complete the survey. The SCCAI and the SIBDQ have been validated [20, 21] to evaluate disease severity and its impact on HRQoL, respectively. The demographic section consisted of basic questions to better assess the study population. The authors created the comprehension questionnaire, which included nine questions regarding procedure-specific complications. It was designed to assess the respondents' comprehension and information retention after watching the video. The questionnaire consisted of multiple-choice questions where patients had to identify which complications were associated with a surgery. Lastly, the surgery preference section allowed patients to indicate their preferred procedure as well as three factors motivating their decision. The factors could be chosen from a list of complications created with the Dubois et al. systematic review [18]. There was a total of 15 factors listed and patients had to select three that had the greater impact on their decision.

The SCCAI includes six questions related to colitis activity. In it, bowel movement frequency during the day, bowel movement frequency during the night, urgency of defecation, presence of blood in stool, general well-being, and extracolonic features are each given a score from 0 to 5 depending on their severity. The total score indicates the severity of disease activity. A higher score means more severe or active disease. Generally, a score below 2 indicates clinical remission [22, 23], and a score above 5 is considered a relapse [24].

The SIBDQ is the short version of the IBDQ. It consists of 10 items scored from 1 (poor HRQOL) to 7 (optimum HRQOL). The SIBDQ is reliable and generally used to detect meaningful changes in HRQOL for a given patient. The mean score for active disease compared to inactive disease were 48 and 59 respectively in the original description of the SIBDQ [25].

Statistical Analysis

Statistical analysis was performed with IBM² SPSS V26. Descriptive statistics were obtained using central tendency and dispersion measures depending on the type of variable. The comparison of proportions was calculated using X2, and nonparametric statistics were used for comparing means when required. Multiple discriminant analysis was also performed using variables resulting in significant differences. Statistical significance was considered reached with p values <0.05.

Results

Out of the 2372 patients managed at the inflammatory bowel disease clinic in 2019, only 390 had a proven diagnosis of UC. Of these, 159 patients were excluded either

because they did not meet the inclusion criteria or declined to participate. Ultimately, 68 of the 231 eligible patients completed the questionnaire (29% response rate) between June 2019 and October 2019 (Figure 1).

Table 1 presents the characteristics of patients. Results indicated that 29 (43%) respondents preferred IPAA and 38 (56%) preferred end ileostomy. One patient did not choose any surgery. Women were more likely to choose end ileostomy over IPAA, while men were less likely to choose end ileostomy over IPAA (67.4% vs. 32.6% as opposed to 37.5% vs. 62.5%, p = 0.017).



Figure 1. Selection of patients

Patients who had their last symptomatic episode further in the past were more likely to choose end ileostomy over IPAA (46% vs. 54% at 6 months as opposed to 65% vs. 35% at 2 years, p = 0.05) (Figure 2). BMI was higher among patients choosing end ileostomy (27 vs 24, p = 0.046). Table 2 provides information about ulcerative colitis activity. Factors related to colitis activity showed no significant impact on patients' choice. Neither the SCCAI and SIBDQ scores nor respondents' comprehension significantly affected patients' choice.

Table 1. Respondents' der	mographics
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Characteristics	No. (%) of respondents $(n = 68)$	
Δαο	respondents (n = 68)	
18-25	6 (9)	
26-35	16 (24)	
36-45	18 (26)	
46-55	19 (28)	
56-65	9 (13)	
Sex		
Female	43 (63)	
Male	25 (37)	
Marital status ^a		
Married	49 (72)	
Single/widowed/divorced	15 (22)	
Employment status ^b		
Looking	1 (2)	
Disabled	4 (6)	
Retired	6 (9)	
Student	2 (3)	
Full time	52 (77)	
Highest educational attainment ^c		
<8 th grade	2 (3)	
High school	11 (16)	
Vocational training	19 (28)	
College	18 (27)	
University	17 (25)	
Body mass index (BMI)		
<18.5	1 (2)	
18.5-24.9	31 (46)	
25-29.9	24 (35)	
30-34.9	7 (10)	
35-39.9	5 (7)	
>39.9	0 (0)	

a: Four respondents did not answer this question.

b: Three respondents did not answer this question.

c: One respondent did not answer this question.

	Table 2	2. Ulce	rative	colitis	activity
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Characteristics	No. (%) of respondents (n = 68)	
Last symptoms ^a		
Ongoing	14 (21)	
<6 months	13 (19)	
6-12 months	8 (12)	
12-24 months	14 (21)	
>24 months	17 (25)	
SCCAI score		
0-2	44 (65)	
3-4	15 (22)	
>4	9 (13)	
SIBDQ score		
61-70	32 (47)	
51-60	22 (32)	
41-50	8 (12)	
31-40	4 (6)	
<31	2 (3)	

a: Two respondents did not answer this question.

Table 3 gives the factors determining patients' choice for IPAA or end ileostomy. The three most common factors cited by patients opting for IPAA were not wanting to have a stoma (76%), having to empty the stoma bag (72%), and stoma-related complications (i.e., hernia, retraction, and stenosis) (38%). The three most common factors cited by patients opting for end ileostomy were fecal incontinence (53%), frequency of stools (42%), and risk of pouchitis (42%).

All SCCAI questions were individually analyzed to determine if any specific symptom had more impact on the choice of procedure. None of the symptoms showed a significant difference in proportions regarding the procedure of choice. Neither the mean score nor the proportion of patients considered in remission or relapse differed between the two groups.

The mean HRQOL and the proportion of patients with a score of 60 or higher did not differ between the two groups.

Multiple discriminant analysis including sex, last symptomatic episode, BMI and different questionnaires results showed gender to be the best predictor, followed by BMI and time of last episode (Wilk's Lambda p = 0.044).

Discussion

Failure or intolerance of medical treatment might indicate the need for surgery in patients with active UC. It has been estimated that approximately 20% to 30% of patients with ulcerative colitis will eventually need a colectomy [26]. For these patients, this step involves a significant lifestyle change. They need a clear and detailed information session to help them choosing between the different surgical options.

Our study identified biological sex as a factor potentially affecting patients' choice for a procedure. Women were more in favor of end ileostomy and risk of fecal incontinence was the most important factor in the group of patients choosing end ileostomy. Women may have experienced more fecal incontinence in their lives because of pregnancy and vaginal delivery or



Figure 2. Patient choice according to time since last symptomatic episode

other medical conditions. Even though fecal urgency was included in the SCCAI questionnaire, fecal incontinence was not well described but could significantly alter patients' preference for a surgical intervention [27]. The risk of vaginal fistula was another factor mentioned in favor of end ileostomy in women.

Patients who had their last symptomatic episode further in the past were more likely to choose end ileostomy over IPAA. Memories of frequent stools and urgency and their impact on daily life might have influenced these patients to choose ileostomy [28–30].

BMI was also higher in the ileostomy group. The standard deviation was 5.5 for ileostomy and 3.7 for IPAA. For this reason, this finding was not judged clinically significant.

The factors influencing patients to choose IPAA seems to be mostly related to the apprehension about the unfamiliar stoma and the disadvantages associated with it rather than the complication of the procedure itself.

Table 3. Factors most important to patients according to procedure of choice^{1,2}

IPAA (n = 29)			
Having a stoma	22 (76%)		
Needing to empty stoma bag frequently	21 (72%)		
Problems associated with stoma	11 (38%)		
End ileostomy (n = 38)			
Fecal incontinence	20 (53%)		
Having frequent stools	16 (42%)		
Risk of pouchitis	16 (42%)		
Risk of anastomotic leak and sepsis	13 (34%)		
Total number of surgeries needed	10 (26%)		
Risk of bowel obstruction	9 (24%)		
Risk of vaginal fistula	6 (16%)		
Antidiarrheal consumption	5 (13%)		
Sexual dysfunction	3 (8%)		

1: Patients were asked to select the three most important factors affecting their choice.

2: Only factors indicated by three or more respondents are displayed.

Although our study population was too small to reveal other significant differences due mainly to recruitment difficulty and lack of survey responses, most patients chose end ileostomy, which is contrary to past reports and practice [30, 31]. This difference from the literature might be explained by the fact that the procedure choice was fictional, and patients did not have to live with the ileostomy and its psychological burden.

Although the risks of surgical interventions are well defined in the literature, this study explored which of these complications were more important to patients in choosing surgical treatment for UC. These results will allow us to work on our future patient information sessions and educational materials to specifically address the factors of greater concern to patients.

This is the first study to analyze patient preference for a type of surgery based on a detailed description of risks associated with each procedure.

One of the limitations of this study is that it included patients with UC but who were not faced with having to choose for an imminent surgery, as reflected in the low SCCAI and SIBDQ scores. As the proportion of patients with UC needing surgery was low, the number of patients would have been insufficient to include only patients waiting for surgery. The study was conducted in a single tertiary medical center with patients treated by different gastroenterologists. Also, we did not know the prevalence of fecal incontinence in our population. While we excluded patients over 65 years of age to have a more homogeneous population, it would have been interesting to know the proportion of patients with fecal incontinence and its impact on surgery choice.

Conclusion

Aside from sex, and time from last flare up, we did not identify other relevant demographic factors or colitis severity aspects affecting patients' theoretical choice of procedure. We were, however, able to identify the issues of greater concern to patients related to each procedure. The wide distribution in the significant elements for patients when having to choose between IPAA and end ileostomy demonstrates the importance of considering their input in preparing information sessions and educational materials designed to assist them in selecting the most appropriate surgical procedure. The most frequent and most severe complications of surgery should always be mentioned, but a detailed discussion—including the seemingly mundane elements associated with either surgery that are most relevant to patientsshould always be undertaken as it might help patients choose and be satisfied with their choice.

Acknowledgment

Gabrielle Major contributed to data collection.

Funding

This study was funded by the Department of Surgery at the Université de Sherbrooke.

Conflict of interest

None.

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