Self-Reported Abdominal Symptoms in Relation to Health Status in Adult Patients With Familial Adenomatous Polyposis

Kaisa Fritzell, Mcs,1,2 • Lars E. Eriksson, Ph.D.1 • Jan Björk, Ph.D.2,3 • Rolf Hultcrantz, Ph.D.2,3 • Lena Wettergren, Ph.D.1

1 Department of Neurobiology, Care Sciences, and Society, Division of Nursing, Karolinska Institutet, Stockholm, Sweden

2 The Swedish Polyposis Registry, Department of Gastroenterology and Hepatology, Karolinska University Hospital, Stockholm, Sweden

3 Department of Medicine, Karolinska Institutet, Stockholm, Sweden

Funding/Support: This work was supported by grants from the Cancer Society in Stockholm and the Center for Healthcare Science at the Karolinska Institute, Sweden.

Financial Disclosure: None reported.

Correspondence: Kaisa Fritzell, Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, 23 300, 141 83 Huddinge, Sweden. E-mail: Kaisa.Fritzell@ki.se

ABSTRACT

BACKGROUND: Patients with familial adenomatous polyposis who undergo surgery to prevent colorectal cancer experience various abdominal symptoms that may affect their physical and mental health.

OBJECTIVE: This study was designed to investigate self-reported presence, frequency, and troublesomeness of abdominal symptoms in such patients in relation to sex, type of surgery, and physical and mental health.

DESIGN: A cohort study with a descriptive and comparative cross-sectional design.

SETTING AND PARTICIPANTS: All adult patients in the Swedish Polyposis Registry (Karolinska University Hospital, Stockholm, Sweden) who were diagnosed with familial adenomatous polyposis, had undergone prophylactic colorectal surgery, and were aged 18 to 75 years were invited to return a mailed questionnaire.

MAIN OUTCOME MEASURES: Self-reported presence, frequency, and troublesomeness of 21 abdominal symptoms were assessed with the Abdominal Symptom Questionnaire. Physical health and mental health were evaluated with the Medical Outcomes Study Short Form 36 Health Survey.

RESULTS: Of 275 eligible patients, 209 (76%) responded. Of respondents, 91% reported having had at least 1 symptom during the last 3 months. All 21 symptoms investigated were reported. A higher number of symptoms was reported by women than by men: mean, 7.55 (SD, 4.89) vs 5.14 (4.49); $P < .01$. No significant difference was found between women and men in overall troublesomeness of symptoms: 3.15 (1.30) vs 3.09 (1.27); $P = .763$. Self-reported number of symptoms was an independent predictor of physical and mental health, with a high number of symptoms related to poor physical and mental health.

LIMITATIONS: The Abdominal Symptom Questionnaire has not been previously used in patients with FAP, and measurement of physical and mental health with the Short Form 36 Health Survey may not capture all aspects of health status in patients with familial adenomatous polyposis.

CONCLUSION: Patients with familial adenomatous polyposis suffer from a wide variety of abdominal symptoms after colorectal surgery. Identification of patients with a high number of abdominal symptoms is especially important because the number of

abdominal symptoms affects patients' physical and mental health.

KEY WORDS: Familial adenomatous polyposis; Abdominal symptoms; Health status; Patient questionnaires; Colorectal surgery.

INTRODUCTION

To prevent colorectal cancer, most patients with familial adenomatous polyposis (FAP) undergo one of the following procedures between the ages of 18 and 20 years: removal of the colon with construction of an ileorectal anastomosis (IRA) or removal of both the colon and rectum with construction of an ileal pouch anal anastomosis (IPAA) or ileostomy.[1,2] Patients with FAP are normally asymptomatic before surgery, but after surgery they report various symptoms, such as an increase in number of bowel movements per day, nighttime defecation, leakage, fecal urgency, difficulty in distinguishing gas from feces, perianal skin problems, and small-bowel obstruction. Most patients also report a need for dietary restrictions[3,4] to avoid disturbing abdominal symptoms.[5] Symptoms have been suggested to be more prevalent in patients with an IPAA than in those with an IRA;[3] knowledge is limited regarding symptoms experienced by patients with an ileostomy.[6] As measured with standardized questionnaires, health status in patients with FAP after prophylactic colorectal surgery has been reported to be equivalent to population norms.[4,6-9]

To explore patients' views of what it is like to live with FAP, our research group conducted focus-group interviews among patients who had undergone prophylactic colorectal surgery.[5] The results showed that abdominal discomfort and pain were important reasons for concern in regard to living with FAP, including insecurity caused by uncertainty about what to eat in order to avoid intestinal problems, as well as a need for extensive planning before participating in social activities. Furthermore, many patients expressed unmet needs for professional support.

A symptom has been defined as a subjective experience reflecting changes in an individual's biopsychosocial functioning, sensations or cognition—as opposed to a sign, which is defined as any abnormality indicative of disease, detectable by the individual or by others.[10] Because the experience of symptoms is considered to be subjective, the patient's perception of symptoms is crucial for the identification of strategies to alleviate or remedy symptoms.[11] In the study reported here, we wanted to investigate abdominal symptoms from the patient's perspective. The aim was to investigate self-reporting by adults with FAP with regard to presence, frequency, and troublesomeness of abdominal symptoms in relation to health status. An additional aim was to study abdominal symptoms in relation to sex and type of colorectal surgery performed.

MATERIALS AND METHODS

This cohort study has a descriptive and comparative cross-sectional design. Ethical approval was granted by the Regional Ethical Review Board in Stockholm. All patients in the national Swedish polyposis registry who were diagnosed with FAP, had undergone prophylactic colorectal surgery, and were aged 18 to 75 years were eligible to participate.

Instruments

Data collection was based on 2 standardized questionnaires: the Abdominal Symptom Questionnaire (ASQ)[12] for abdominal symptoms, and the Medical Outcomes Study Short Form 36 Health Survey (SF-36)[13] for health status, including physical and mental health.

The original ASQ was divided into 3 parts. The questionnaire used in this study was based on the first part, presenting a list of 21 general abdominal symptoms and asking respondents to indicate (by answering yes or no) whether they had been troubled by any of these symptoms during the last 3 months. If they answered "yes" they were asked to indicate whether the symptom occurred "every day", "every week", or "every month". To assess the degree of "troublesomeness" of symptoms, patients were also asked to rate the severity of each symptom on a 7-point Likert-style scale (1 = "mild" and 7 = "very severe"). The complete ASQ was originally designed to identify 3 functional gastrointestinal disorders—dyspepsia, gastroesophageal reflux symptoms, and irritable bowel syndrome—and the questionnaire has shown acceptable sensitivity and specificity in identifying persons with dyspepsia and irritable bowel syndrome.[12]
Five additional abdominal symptoms not included in the ASQ were added to the questionnaire for the present study. These items asked the respondents to indicate (by answering yes or no) whether they had experienced the following problems: pain when eating certain foods, increased bowel movements, daytime leakage, nighttime leakage, and perianal soreness.

The SF-3613 consists of 36 items: 35 items measure the following 8 dimensions of health status: physical functioning, role-physical (which refers to role limitations due to physical difficulties), bodily pain, general health, vitality, social functioning, roleemotional (which refers to role limitations due to emotional difficulties), and mental health; 1 item assesses perceived differences in health status over the past year. Response

choices vary from 2 to 6 possibilities. In addition to the item concerning health transition over the past year, 20 items refer to the 4 previous weeks, and 15 items concern the present. Raw scores for each item are coded, summed, and transformed into a scale from 0 (worst possible health status) to 100 (best possible health status), following standard SF-36 scoring algorithms.[13] Based on the 8 dimensions, 2 summary scales have been constructed for physical and mental health: the physical component summary and the mental component summary. The physical component summary score is primarily a measure of the physical functioning, role-physical, bodily pain, and general health dimensions, whereas the mental component summary score mainly encompasses vitality, social functioning, role-emotional, and mental health.[14] The Swedish version of the SF-36 has shown satisfactory results regarding reliability and validity.[15,16]

Demographic and clinical characteristics of all eligible patients were collected from the national Swedish Polyposis Registry.

Procedures

A letter inviting participation in the study was sent to all patients in the Swedish Polyposis Registry who fulfilled the eligibility criteria. The letter included information about the study and contained the package of questionnaires. The letter stressed that participation was voluntary and that nonparticipation would not affect a patient's care or treatment. Patients who were willing to participate were asked to complete the questionnaire and return it in an enclosed postage-paid envelope. Patients who did not return the questionnaire were sent a reminder after 3 weeks. All returned questionnaires were read through to detect missing data, and participants were contacted by phone for completion when necessary.

Data Analysis

Statistical analyses were performed with the Statistical Package for Social Sciences (SPSS) for Windows, version 17.0 (SPSS Inc, Chicago, IL). Missing values for the SF-36 were substituted if half or more of the items within a scale were responded to; that is, a person-specific mean score was calculated based on the existing answers. The overall troublesomeness of symptoms as measured by the ASQ was calculated by adding up the scores (possible score, 1–7) for all symptoms and dividing the sum by the number of reported symptoms.

Descriptive statistics were computed for scales and standardized questions. Independent *t* tests and 1-way ANOVA were calculated to investigate potential differences in mean values between groups (eg, sex, age at time of last colorectal surgery, type of surgery). Relationships between variables (number of symptoms, perceived troublesomeness of symptoms, age at study entry, age at first and last surgery) were studied using Pearson correlation coefficients. Coefficients of 0.29 or less were interpreted as low, 0.30 to 0.49 as moderate, and greater than 0.49 as high.[17] Two 3-step hierarchical multiple regression analyses were performed to determine predictors of the physical and mental health component summaries of the SF-36. Variables theoretically considered to have an impact on patients' physical and mental health were entered into the model. In the first step, age, sex, and FAP in the family were included. In the second step, age at last colorectal surgery and type of performed surgery (IRA, IPAA, or ileostomy) were forced into the model, and in the third step, number of symptoms and troublesomeness were forced into the model. A statistical significance level of $P < .05$ was applied in all analyses.

RESULTS

A total of 276 patients met eligibility criteria and were invited to participate in the study. One patient did not speak Swedish and was therefore excluded. Of the remaining 275 patients, 209 (76%) consented to participate and were enrolled in the study. Demographic and clinical characteristics of the study participants are presented in Table 1. The 209 participants represented 111 of 135 known Swedish families with FAP (mean number of individuals per family, 1.9; range, 1–22). No statistically significant differences in demographic and clinical characteristics were found between participants and nonparticipants. Furthermore, no statistically significant differences between men and women regarding demographic and clinical characteristics were observed (data not shown). Removal of the colon or colorectum (with ileorectal anastomosis, ileal pouch anal anastomosis, or ileostomy) had been performed in all but 3 patients, who had undergone a segmental resection of the colon, classified as "other" (Table 1).

Presence, Frequency, and Troublesomeness of Symptoms

Patients' responses to the ASQ regarding presence, frequency, and troublesomeness of abdominal symptoms are shown in Table 2. A total of 190 patients (91%) reported having had at least 1 symptom during the past 3 months. All 21 symptoms included in the

ASQ were reported, with diarrhea being the most commonly reported symptom overall, followed by borborygmi (stomach growling), and nighttime urge of defecation. In patients with an IRA, the most prevalent symptom was diarrhea; in patients with an IPAA, borborygmi; and in patients with an ileostomy, nighttime urge of defecation (data not shown). Although relatively rare (occurring in 13% of patients), constipation was the symptom with the highest percentage of patients (86%) reporting daily or at least once per week occurrence, closely followed by borborygmi (84%), and belching (84%). Interfering flatus had the highest mean value of troublesomeness, closely followed by alternating diarrhea and constipation and abdominal discomfort or pain at defecation. Presence and troublesomeness of abdominal symptoms are analyzed according to sex and type of prophylactic procedure in Table 3. Women reported a significantly higher number of symptoms compared with men. No significant differences in number of symptoms were found when the types of prophylactic colorectal surgery were compared. The overall mean score for troublesomeness of abdominal symptoms in our patients was 3.12 (SD, 1.29; range, 1.06.6). No statistically significant differences were found between men and women or among different types of prophylactic procedures in degree of reported troublesomeness of symptoms. Perceived troublesomeness correlated moderately with the number of reported symptoms (r = 0.44).

Regarding the 5 additional abdominal symptoms included in the questionnaire, 167 patients (80%) reported having increased bowel movements, 136 patients (65%) reported pain when eating certain food, 84 patients (40 %) reported perianal soreness, 61 patients (29%) reported daytime leakage, and 82 patients (39%) reported nighttime leakage.

Physical and Mental Health

Hierarchical multiple regression analyses showed similar predictors for self-reported physical health and mental health as assessed with the SF-36 (Table 4). In the first step, physical health was significantly predicted by the variables sex and age, whereas mental health was significantly predicted by age and presence of FAP in the family. Physical health declined with increasing age, while mental health remained stable or improved. The second step investigated the impact of time since last colorectal surgery and type of colorectal surgery (IRA, IPAA, or ileostomy). These variables had only a negligible effect on physical and mental health when the effects of sex, age, and FAP in the family were already accounted for. In the third step, the addition of number of symptoms and

troublesomeness showed that number of symptoms had the largest impact on physical and mental health in the model. When the variances of the other independent factors were held constant, only number of self-reported symptoms and age were significant contributors to the model. Finally, the independent variables accounted for 33% of the variance of the dependent variables physical and mental health scores.

DISCUSSION

The results of our study showed that patients with FAP experience a large number of abdominal symptoms after prophylactic colorectal surgery regardless of the type of procedure performed, with a significantly higher number of symptoms reported by women than by men. Moreover, the number of self-reported symptoms was the strongest predictor of patients' physical and mental health. As expected, symptoms such as diarrhea, nighttime urge of defecation, and flatus, which were previously reported in patients with FAP after prophylactic colorectal surgery,[3] were frequently reported by patients in the current study. However, symptoms not previously reported, such as borborygmi, abdominal distension, abdominal discomfort or pain relieved by defecation, and belching, were reported by 30% to 62% of our patients. Although such symptoms have been spontaneously communicated by patients at our clinic, the number of patients reporting them in this study was surprisingly high. In comparison, Agréus et al18 found that corresponding symptoms were reported by 4% to 23% of individuals in a general Swedish population.18 Diarrhea, borborygmi, nighttime urge of defecation, and abdominal distension were the most prevalent and most frequently occurring symptoms in our patients, although they were not considered the most troublesome. Perceived troublesomeness seems to be independent of prevalence and frequency in the present study. Also, perceived troublesomeness was only moderately related to number of symptoms, indicating that higher numbers of symptoms do not necessarily mean a greater degree of troublesomeness.

To our knowledge, only 1 study has investigated bowel function in patients with FAP and ileostomy,[6] reporting excellent bowel function. In the present study, however, patients with an ileostomy did not differ from those with an IRA or IPAA in number or troublesomeness of symptoms. This subgroup of patients should be further studied, preferably in a multicenter collaboration to gain a sufficient sample size. Nevertheless, the findings of the current study should be taken into consideration in the care of patients

with an ileostomy: Such patients may need symptom management to the same extent as patients with an IRA or IPAA but may not have the same access to health care because they have no or less frequent endoscopic surveillance of the stoma and neoterminal ileum.

In contrast to other reports,[3,7] the present study found no significant differences in number of symptoms when patients with different types of surgery are compared. A possible explanation for the disparities in results is that the abdominal symptoms assessed in the current study are not exclusively related to bowel dysfunction. Nonspecific abdominal symptoms may be less dependent on the type of colorectal surgery performed. Another explanation could be that the results of this study are based on self-reported data reflecting patients' subjective perception of abdominal symptoms, which may contrast with health professionals' evaluation of patients' symptoms. Furthermore, surgical complications and comorbidity were not investigated in the current study, although previous reports show that these variables can affect bowel function.[19]

To our knowledge, this is the first study comparing men and women with FAP after prophylactic colorectal surgery with respect to number of symptoms. As in the general population,[18] in patients with FAP a significantly higher number of symptoms was reported by women than by men. Attempts have been made to explain why women report symptoms and health complaints to a greater extent than men do. It has been suggested that women have a greater willingness than men to report symptoms they perceive.[20] However, the difference between healthy men and women regarding bowel symptoms may at least to some extent be explained by more frequent colonic dysfunction in women.[21] The fact that these differences remain after colon removal suggests that the influence of the colon may be overestimated and that other, not yet fully understood mechanisms are important.

In line with reports from Swedish population norms,[16] age was a significant predictor of physical and mental health in the current study, although the multiple regression analyses revealed that number of symptoms had the greatest impact on patient's physical and mental health. Contrary to expectation, troublesomeness of symptoms was not a significant predictor of physical and mental health. Future studies of symptom perception should assess the different ways that specific symptoms influence

daily life. The regression models used in this study explained more than 30% of the variance of physical and mental health, suggesting that efforts to alleviate or remedy abdominal symptoms can be important in improving overall physical and mental health in patients with FAP who undergo colorectal surgery.

The study had a number of specific strengths. First, the combination of a high response rate and a large number of patients with IRA, IPAA, or ileostomy resulted in a large cohort of patients in which abdominal symptoms could be investigated. Second, measuring a broad array of abdominal symptoms—not only the symptoms usually assessed in such patients—turned out to be relevant because symptoms such as borborygmi and abdominal distension were frequently reported by our patients, indicating their importance in this context. Third, the sample size allowed for multivariate analysis, making it possible to investigate the influence of several factors at the same time.

Some limitations of the study should also be noted. First, the ASQ was originally developed to diagnose patients with functional gastrointestinal disorders[12] and has not been previously used in patients with FAP. Second, measurement of physical and mental health using the standardized instrument SF-36 may not capture all aspects of health status in patients with FAP.[4,19]

CONCLUSIONS

The results of the current study show that patients with FAP suffer from a wide variety of abdominal symptoms, independent of type of prophylactic colorectal surgery performed. It is therefore crucial to base symptom management on a systematic inventory of patients' perception of symptoms, rather than asking for symptoms generally accepted as being related to bowel dysfunction in patients with FAP after colorectal surgery. Symptoms such as, interfering flatus, borborygmi and abdominal distension can be alleviated with pharmacological treatment and dietary restrictions. Identification of patients with a high number of abdominal symptoms is especially important because the number of abdominal symptoms was found to influence patients' physical and mental health. Furthermore, symptom management needs to be followed up by specialist physicians or specialist nurses familiar with FAP. Future studies should analyze patients' views regarding specific symptoms, how troublesome they are perceived to be, and their

impact on patients' lives, as well as their relation to quality of care. Because abdominal symptoms are perceived individually, a qualitative approach may be useful for the purpose.

ACKNOWLEDGMENTS

The authors thank all the patients who generously participated in this study.

REFERENCES

1. Bjork J, Akerbrant H, Iselius L, et al. Outcome of primary and secondary ileal pouch-anal anastomosis and ileorectal anastomosis in patients with familial adenomatous polyposis. *Dis Colon Rectum.* 2001;44:984-992.

2. Vasen HF, Moslein G, Alonso A, et al. Guidelines for the clinical management of familial adenomatous polyposis (FAP). *Gut.* 2008;57:704-713.

3. Aziz O, Athanasiou T, Fazio VW, et al. Meta-analysis of observational studies of ileorectal versus ileal pouch-anal anastomosis for familial adenomatous polyposis. *Br J Surg.* 2006;93:407-417.

4. Osterfeld N, Kadmon M, Brechtel A, Keller M. Preoperative and postoperative quality of life in patients with familial adenomatous polyposis. *Dis Colon Rectum.* 2008;51:1324-1330.

5. Fritzell K, Persson C, Bjork J, Hultcrantz R, Wettergren L. Patients' views of surgery and surveillance for familial adenomatous polyposis. *Cancer Nurs.* 2010;33:E17-23.

6. Ko CY, Rusin LC, Schoetz DJ, et al. Using quality of life scores to help determine treatment: is restoring bowel continuity better than an ostomy? *Colorectal Dis.* 2002;4:41-47.

7. Hassan I, Chua HK, Wolff BG, et al. Quality of life after ileal pouch-anal anastomosis and ileorectal anastomosis in patients with familial adenomatous polyposis. *Dis Colon Rectum.* 2005;48:2032-2037.

8. Ko CY, Rusin LC, Schoetz DJ, Jr., et al. Does better functional result equate with better quality of life? Implications for surgical treatment in familial adenomatous polyposis. *Dis Colon Rectum.* 2000;43:829-837.

9. Ko CY, Rusin LC, Schoetz DJ, Jr., et al. Long-term outcomes of the ileal pouch anal anastomosis: the association of bowel function and quality of life 5 years after surgery. *J Surg Res.* 2001;98:102-107.

10. Harver A, Mahler DA. The symptom of dyspnea. In: Mahler DA ed. *Dyspnea*. Mount Kisco, NY: Futura Pub. Co.; 1990:1-53.

11. Haworth SK, Dluhy NM. Holistic symptom management: modelling the interaction phase. *J Adv Nurs.* 2001;36:302-310.

12. Agréus L, Svardsudd K, Nyren O, Tibblin G. Reproducibility and validity of a

postal questionnaire. The abdominal symptom study. *Scand J Prim Health Care.* 1993;11:252-262.
13. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care.* 1992;30:473-483.
14. Ware JE, Kosinski M. Interpreting SF-36 summary health measures: a response. *Qual Life Res.* 2001;10:405-420.
15. Sullivan M, Karlsson J, Ware JE, Jr. The Swedish SF-36 Health Survey--I. Evaluation of data quality, scaling assumptions, reliability and construct validity across general populations in Sweden. *Soc Sci Med.* 1995;41:1349-1358.
16. Sullivan M, Karlsson J, Taft C. *SF-36 Hälsoenkät. Svensk Manual och Tolkningsguide, 2:a upplagan. [Swedish Manual and Interpretation Guide, 2nd ed]*. Göteborg, Sweden: Sahlgrenska University Hospital; 2002.
17. Fayers PM, Machin D. *Quality of Life: The Assessment, Analysis, and Interpretation of Patient-Reported Outcomes*. 2nd ed. Chichester; Hoboken, NJ: J. Wiley; 2007.
18. Agréus L, Svardsudd K, Nyren O, Tibblin G. The epidemiology of abdominal symptoms: prevalence and demographic characteristics in a Swedish adult population. A report from the Abdominal Symptom Study. *Scand J Gastroenterol.* 1994;29:102-109.
19. Douma KF, Bleiker EM, Vasen HF, Gundy CM, Aaronson NK. Quality of life and consequences for daily life of familial adenomatous polyposis (FAP) family members [published online ahead of print April 5, 2010]. *Colorectal Dis.* doi:10.1111/j.1463-1318.2010.02275.x.
20. van Wijk CM, Kolk AM. Sex differences in physical symptoms: the contribution of symptom perception theory. *Soc Sci Med.* 1997;45:231-246.
21. Kanazawa M, Palsson OS, Thiwan SI, et al. Contributions of pain sensitivity and colonic motility to IBS symptom severity and predominant bowel habits. *Am J Gastroenterol.* 2008;103:2550-2561.

Table 1. Clinical characteristics of patients (n=209)

	mean (SD; range)	n	%
Age	49 (14; 18-75)		
Sex			
Men	48 (15; 18-75)	93	44
Women	49 (13; 23-74)	116	56
Living situation			
Partnered		139	67
Single		61	29
Living with parents or other		9	4
Occupation			
Working		123	59
Student		12	8
Retired		42	20
Disability pension		17	8
Sick-listed		11	5
Participants having children		144	69
FAP in the family[a]		169	81
Age at diagnosis	26 (12; 3-57)		
Age at first colorectal surgery, years	28 (11; 5-58)		
Time since first colorectal surgery to study, years	21 (12; 1-50)		
Times since last colorectal surgery to study, years	14 (10; 1-50)		
Last colorectal surgery			
IRA[b]		71	34
IPAA[c]		82	39
Ileostomy		39	19
Continent ileostomy		14	7
Other		3	1
Total number of colorectal procedures			
One		132	63
Two		66	32
Three or more		11	5
Upper gastrointestinal surgery		23	11
Desmoid tumor		20	10
FAP related cancer		50	24

[a]Having family members with FAP
[b]IRA=ileorectal anastomisis
[c]IPAA=ileal pouch anal anastomosis

Table 2. Self-reported symptoms, prevalence, symptoms frequent every day or week the three preceding months and troublesomeness, as measured with the Abdominal Symptom Questionnaire

	Prevalence (n=209)	Symptom present every day or week	Troublesomeness[a]	
	%	%	mean	(range)
Diarrhea	67	73	3.81	(1-7)
Borborygmi	62	84	3.46	(1-7)
Nighttime urge of defecation	60	80	3.34	(1-7)
Abdominal distension	50	77	3.58	(1-7)
Abdominal discomfort or pain relieved by defecation	42	58	3.38	(1-7)
Interfering flatus	34	82	4.01	(1-7)
Feelings of incomplete defecation	33	81	3.6	(1-7)
Uncomfortable feeling of fullness after meals	33	65	3.63	(1-7)
Nausea	32	52	3.42	(1-7)
Retrosternal pain	32	43	3.34	(1-7)
Belching	31	84	2.69	(1-7)
Heartburn	29	59	3.36	(1-7)
Early satiety	28	78	3.36	(1-6)
Abdominal discomfort or pain at defecation	28	67	3.9	(1-7)
Reflux episodes	23	65	3.43	(1-6)
Loss of appetite	19	58	3.53	(1-6)
Constipation	13	86	3.75	(1-7)
Altering diarrhea and constipation	10	60	4	(2-7)
Vomiting	9	42	3.84	(1-7)
Loss of weight	8	NA[b]	NA[b]	
Dysphagia	6	54	3.38	(1-6)

Missing data: prevalence n=2, frequency n=14

[a] possible score 1-7

[b]NA=not applicable

Table 3. Differences in self-reported symptoms, number and troublesomeness of symptoms, as measured with the Abdominal Symptom Questionnaire (n=209)

	Number of symptoms[a]				Symptom troublesomeness[b]			
	Mean	SD	Range		Mean	SD	Range	
Males	5.14	4.49	0-18	p<0.001[c]	3.09	1.27	1.0-6.6	p=0.763[c]
Females	7.55	4.89	0-18		3.15	1.30	1.0-6.2	
IRA[e]	6.51	5.04	0-17	p=0.276[d]	3.09	1.28	1.0-6.6	p=0.994[d]
IPAA[f]	7.07	4.84	0-18		3.10	1.27	1.0-6.2	
Ileostomy	5.56	4.41	0-14		3.12	1.38	1.0-6.0	

[a]possible number of symptoms=21
[b]possible range 1-7
Tested for differences by t-test[c] and ANOVA (n=192)[d]
[e]IRA=ileorectal anastomosis, [f]IPAA=ileal pouch anal anastomosis

Table 4. Hierarchical multiple linear regression analyses with PCS[a] and MCS[b] as the dependent variables (participants=183)

		PCS				MCS			
		β standardized	R^2 change	R^2 adjusted	F	β standardized	R^2 change	R^2 adjusted	F
Step 1			0.131*	0.117	9.018*		0.127*	0.112	8.641*
	Gender[c]	-0.191*				-0.088			
	Age	-0.295*				0.287*			
	FAP in the family	-0.106				-0.205*			
Step 2			0.017	0.114	4.339*		0.010	0.102	3.957*
	Gender	-0.201*				-0.092			
	Age	-0.270*				0.280*			
	FAP in the family	-0.096				-0.205*			
	Time since last surgery	0.000				-0.015			
	IRA	-0.061				0.034			
	IPAA	0.061				0.140			
	Ileostomy	0.079				0.049			
Step 3			0.217*	0.332	11.043*		0.226*	0.329	10.923*
	Gender	-0.078				0.031			
	Age	-0.332*				0.215*			
	FAP in the family	0.002				-0.103			
	Time since last surgery	0.051				0.038			
	IRA	-0.111				-0.012			
	IPAA	-0.007				0.075			
	Ileostomy	0.066				0.037			
	Number of symptoms	-0.465*				-0.459*			
	Troublesomeness	-0.066				-0.093			

*p<0.01

[a]PCS=physical component summary score, [b]MCS=mental component summary score (measured with the SF-36). The scores for PCS and MCS range from 0 to 100 with higher scores indicating better health status.

[c]Men=1, Women=2