

Restorative proctocolectomy in patients with ulcerative colitis: a cross-sectional Danish population study on function and quality of life

S. Brandsborg*, A. Tøttrup*, J. Nicholls† and S. Laurberg*

*Colorectal Surgical Unit, Aarhus University Hospital, Aarhus, Denmark and †Imperial College, London, UK

Received 16 November 2012; accepted 5 February 2013; Accepted Article online 4 May 2013

Abstract

Aim The study evaluated function and quality of life (QoL) in all patients having restorative proctocolectomy (RPC) in Denmark for ulcerative colitis (UC) from 1980 to 2010. Inclusion of all patients in one country has never previously been achieved.

Method All patients who had had a RPC in Denmark, from the first case in 1980 to the last case in 2010, were studied. A cross-sectional questionnaire survey was performed, and function and QoL were assessed using a standardized questionnaire – the Short-Form 36 (SF36) – and the inflammatory bowel disease questionnaire (IBDQ).

Results The median duration of follow up was 11 (range, 1–30) years. Apart from deaths, pouch failures and research protection, data on function and QoL were obtained from 1047 (85%) of 1229 patients who had a functioning pouch at the time of the investigation. More female patients than male patients experienced urgency (56% *vs* 44%, $P = 0.0021$). The median number of bowel movements per 24 h was 7 (range, 1–23) in female patients and 6 (range, 1–20) in male patients ($P < 0.001$). Pad usage was more frequent among female patients than among male patients (62% *vs* 38%, $P < 0.001$). A higher incidence of major incon-

tinence ($P = 0.009$) and use of pads ($P = 0.01$) was found among patients who had been operated on 21–30 years previously compared with those operated on 11–20 years previously. The prevalence of urgency was higher in patients who received surgery 0–10 years previously compared with 11–20 years previously ($P = 0.009$). The total IBDQ score was higher in male patients than in female patients ($P < 0.001$). Male patients scored higher in five of eight SF36 domains ($P < 0.001$).

Conclusion Female patients had more urgency, a higher frequency of defaecation and higher pad usage. This was associated with a reduced QoL. Nevertheless, RPC resulted in good function and a high degree of satisfaction in most patients.

Keywords Restorative proctocolectomy, bowel function, quality of life

What is new in this paper?

This study is the first to evaluate bowel function and quality of life in a national cohort of patients having restorative proctocolectomy for ulcerative colitis. Gender was the only factor related to worse function. There was no difference for any of the other factors considered.

Introduction

Restorative proctocolectomy (RPC) was introduced in 1978 for patients with ulcerative colitis (UC) [1] and has been performed over a 30-year period in Denmark. The number of operations is currently about 100 per year in a population of approximately 5.5 million. Successful RPC surgery requires trained surgeons, and

some of the best results are obtained in specialized centres with high volume [2], as has also been shown for patients with UC undergoing acute colectomy [3,4].

Several studies conclude that frequency of defaecation after RPC is satisfactory and stable over time but other parameters, such as urgency, faecal soiling and incontinence during the day and at night, may deteriorate [5–7]. Most studies reporting quality of life (QoL) have found this to be good [8,9], but function and QoL are not always accurately determined owing the

Correspondence to: S. Brandsborg, Colorectal Surgical Unit, Aarhus University Hospital, Tage-Hansens gade 2, 8000 Aarhus C, Denmark.
E-mail: soebra@rm.dk

use of unvalidated questionnaires and poor symptom definitions. This makes the results difficult to interpret.

The aim of the present study was to identify the total Danish cohort of patients having RPC for UC from 1980 to 2010, and to evaluate function and QoL in a population-based study.

Method

The National Board of Health and the Danish Data Protection Agency approved the study. In Denmark, RPC surgery has been performed at Aarhus University Hospital, Copenhagen University Hospital, Odense University Hospital, Aalborg Hospital, Hvidovre Hospital and Herlev Hospital (stopped performing RPC surgery in 2010). Surgeons at Gentofte Hospital and Glostrup Hospital performed RPC surgery from 1980 to 1993 and from 1989 to 1992, respectively. We identified 1757 Danish patients who had undergone RPC at these hospitals as follows.

Prospective lists of 524 RPC patients were available from Hvidovre Hospital and from Aarhus University Hospital for the period 1985–1998. The validity of the registrations was checked by asking patients in a letter if they had had RPC surgery ($n = 348$) or through review of medical records and pathology reports ($n = 176$). A total of 520 patients were identified. We found 2486 potential RPC patients in the Danish National Patient Registry (NPR), using a combination of broad surgical procedure and diagnostic codes (see Appendix I). RPC status was determined either by letter ($n = 1270$) or through review of medical records and pathology reports ($n = 1216$). Of these 2486, we identified 1237 RPC patients who had actually had an RPC.

The NPR contains information on all nonpsychiatric hospital admissions in Denmark from 1977 onwards, including diagnosis and surgical procedure. It uses the International Classification of Diseases (ICD) and, since 1995, the Nordic Classification for Surgical Procedures (NCSP). Before 1995, the classification of surgical procedures was performed according to a unique Danish classification system. Completeness of inflammatory bowel disease (IBD) registration in the Danish NPR has been shown to be high (94%), with validity estimates for registered UC diagnoses of 90% when using a pathology registry as reference [10].

All Danish medical registries use a unique civil registration number, which is given at birth. It is kept in the Civil Registration System along with information on date of birth, residency and death. This number is the foundation of linking registry data in Denmark.

When patients were diagnosed with Crohn's disease along with UC, we used the Danish Pathology Register

(which contains pathology reports on specimens from hospitals in Denmark since 1968) and careful review of medical records to clarify diagnosis.

Of the 1757 patients, 58 had died at the time of the survey, 130 had had the pouch removed, 64 had a diverting stoma and 276 requested research protection (this means that they did not want to be contacted or involved in any research, although their existing information in the registry or medical files could still be used). This left 1229 RPC patients with a functioning pouch. These patients were sent questionnaires on pouch function and QoL. Of the 1057 (86%) who responded, 10 declined to participate. The study thus included 1047 patients with a preoperative diagnosis of UC (Fig. 1). Of these 1047, 12 were diagnosed with Crohn's disease postoperatively and were included in the analysis on an intention-to-treat basis.

Questionnaires

Inflammatory bowel disease questionnaire

The Inflammatory Bowel Disease Questionnaire (IBDQ) was designed to assess disease-specific QoL in patients with inflammatory bowel disease. Additionally, it has been validated in patients undergoing RPC for UC [11]. It consists of 32 items grouped into four dimensions, including bowel symptoms, systemic symptoms, emotional function and social function. The total score ranges from 32 to 224, with a higher score indicating better health. It is widely used and has been translated into several languages, including Danish. It is recommended that the total score, and not the dimensions, should be used when applied to RPC patients [11] and we have adapted this recommendation.

SF36

The SF36 measures generic health-related QoL. It consists of 36 items measuring eight dimensions of health, including: physical functioning (PF); social functioning (SF); role limitations due to emotional (RE) and physical problems (RP); mental health (MH); energy and vitality (VT); body pain (BP); and general health perception (GH). The score ranges from 0 to 100, with a higher score indicating better health. The SF36 version 2 (v2) was used in this study because it has improved reliability compared with the original version [12].

The median SF36v2 results of our patients were compared with the published median SF36-norm for a Danish population of the same age because no published Danish data on SF36v2 exist. It was thus only possible directly to compare five dimensions (PF, BP, GH, SF and VT). A difference of ≥ 10 points was considered clinically significant [13]. The SF36 has

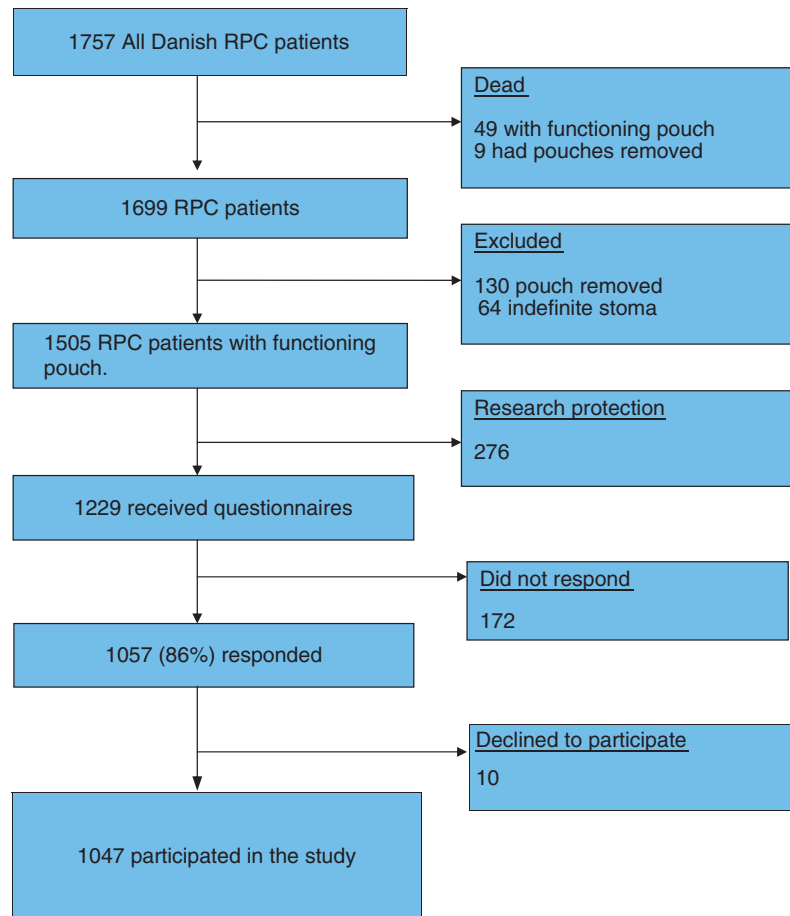


Figure 1 Flow chart of patient recruitment. RPC, restorative proctocolectomy.

previously been shown to be sensitive to variations in health-related QoL for patients with RPC [5,14,15].

Function

Function was assessed by a questionnaire specifically developed for the purpose. It consisted of 13 different items concerning bowel function. Experienced pouch surgeons, nurses and patients contributed to its development of the questionnaire. Before the final survey, semistructured interviews were performed and a pilot study was undertaken to optimize the questions. Patients were instructed only to consider the preceding 2 weeks when answering questions about bowel function. Urgency was defined as the inability to defer defaecation and was quantified according to time in minutes. Major incontinence was defined as uncontrolled loss of stool and minor incontinence as seepage (mark on pad or underwear).

Data analysis

Patients were divided into three 'time' groups according to the interval from RPC to the present assessment

(0–10, 11–20 and 21–30 years). Symptoms were dichotomized according to whether they were present or absent. The results are expressed as median (range) when continuous and as number (percentage) when categorical. Statistical analysis was performed using the Mann–Whitney *U*-test, the Kruskal–Wallis test, Spearman's correlation coefficient and the χ^2 test. A *P*-value of < 0.05 was considered statistically significant.

Results

Patients

Details of 1047 participants and 182 patients who did not participate are given in Table 1. The distribution and baseline characteristics of patients according to years since RPC are summarized in Table 2. The median period of follow up was 11 (1–30) years.

Bowel function

Significantly more female patients experienced urgency than male patients (56% vs 44%, *P* = 0.0021). There

Table 1 Details of 1229 patients sent the questionnaires.

	Response	No response/declined to participate
Patients	1047 (85)	182 (15)
Years from RPC	11 (1–30)	10 (1–29)
Age (years)	47 (14–84)	44 (12–80)
Gender		
Male	540 (52)	120 (66)
Female	507 (48)	62 (34)

RPC, restorative proctocolectomy.

Values are given as *n* (%) or median (range).

Table 2 Patients grouped according to the interval from restorative proctocolectomy (RPC) to the present assessment.

	Interval from RPC		
	0–10 years	11–20 years	21–30 years
Patients	514	368	165
Age (years)	41 (14–84)	47 (25–81)	53 (33–84)
Gender			
Male	269	194	77
Female	245	174	88

Values are given as *n* or median (range).

was no correlation between age and urgency for female patients or male patients. There was a significant gender difference in the median frequency of defaecation in 24 h; seven [1–23] for female patients and six [1–20] for male patients ($P < 0.001$). Pad usage was more frequent among female patients (62% *vs* 38%, $P < 0.001$). No further gender difference was found for other parameters of function.

The categorical bowel-function data were calculated from time since RPC. There was an overall significant difference in the distribution of patients for urgency, major incontinence and use of pads (Table 3). There was a significantly higher incidence of major incontinence ($P = 0.009$) and use of pads ($P = 0.01$) among patients operated on 21–30 years previously than 11–20 years previously. Pad usage was also significantly more common in patients operated on 21–30 years previously compared with 0–10 years previously ($P = 0.003$). The proportion of patients with urgency was significantly higher for patients operated on 0–10 years previously compared with 11–20 years previously ($P = 0.009$). The median number of bowel movements in 24 h was seven [1–23] for the three RPC “time” groups.

There were no differences between the three “time” groups in diurnal and nocturnal frequency of defaecation,

the use of antibiotics and/or antidiarrhoeal medication, feeling of incomplete evacuation and minor incontinence.

IBDQ

The total IBDQ score was significantly higher in male patients than in female patients: 194 (74–224), $n = 523$, *vs* 183 (69–221), $n = 483$ ($P < 0.001$) (Fig. 2). A significantly different median IBDQ score among the three time groups was found, with the highest score for patients operated on 21–30 years previously [193 (91–224)] and the lowest for patients operated on 0–10 years previously [186 (69–224)] ($P = 0.004$).

SF36

The SF36 dimensions for RPC patients are shown in Fig. 3. Male patients scored significantly higher for RP, BP, GH, VT and MH compared with female patients ($P < 0.001$). There was no difference between the three ‘time’ groups in any of the domains. Compared with a reference group with median scores of 77 and 75 in GH and VT, respectively, RPC patients scored lower. No difference between the reference group and RPC patients was found in any of the other SF36 domains. Missing data ranged from 3 to 37 across dimensions.

Discussion

This cross-sectional study aimed to evaluate function and quality in an entire national population of RPC patients. This has never been performed previously. Overall function and QoL in RPC patients were good. Female patients had significantly more bowel movements and urgency, higher use of pads and reduced generic and condition-specific QoL. Allowing for deaths, pouch failure and research protection, we were able to obtain data on function and QoL in 1047 of 1229 patients with a functioning pouch. This is 85%, which is a very high response rate for this type of study. Our results are thus derived from a large unselected cohort followed for up to 30 years after RPC and are representative of an entire national population as far as is practically possible. No other study has achieved this, and few cover such a long period. Most are large single-centre experiences that might represent selected material compared with nationwide data. Hahnloser *et al.* [16] describe function and QoL 20 years after RPC in a single institution and Tekkis *et al.* [7] report the results from the UK Ileal Pouch Registry that by no means are on a national scale.

Table 3 Function according to years from restorative proctocolectomy (RPC) in Danish patients diagnosed with ulcerative colitis (UC) preoperatively.

Variable	Interval from RPC			P
	0–10 years n (%)	11–20 years n (%)	21–30 years n (%)	
Bowel movements during the day < 1 (i.e. not every day)				
1–3	1 (0.2)	1 (0.3)		0.39
4–7	82 (16.2)	63 (17.4)	31 (18.9)	
8–10	302 (59.7)	237 (65.5)	101 (61.6)	
> 10	89 (17.6)	49 (13.5)	23 (14)	
	32 (6.3)	12 (3.3)	9 (5.5)	
Bowel movements at night				
0 (i.e. never)	75 (14.8)	36 (9.9)	18 (11.0)	0.084
< 1 (i.e. not every night)	154 (30.4)	115 (31.8)	48 (29.3)	
1–2	196 (38.6)	157 (43.4)	76 (46.3)	
> 2	82 (16.2)	54 (14.9)	22 (13.4)	
Stool consistency				
Solid	18 (3.5)	11 (3.0)	9 (5.5)	0.367
Semisolid	421 (82.6)	305 (84.5)	127 (77.9)	
Watery	71 (13.9)	45 (12.5)	27 (16.6)	
Episodes of sudden and severe urge to defaecate				
Yes	246 (48.3)	142 (39.3)	66 (40.2)	0.018
No	263 (51.7)	219 (60.7)	98 (59.8)	
Number of episodes per 24 h of a sudden and severe urge to defaecate*				
< 1 (i.e. not every day)	98 (40.1)	61 (43.3)	28 (42.4)	0.599
1–3	87 (35.7)	51 (36.2)	27 (40.9)	
4–7	40 (16.4)	23 (16.3)	10 (15.2)	
8–10	8 (3.3)	4 (2.8)	1 (1.5)	
> 10	11 (4.5)	2 (1.4)		
Ability to suppress the sudden and severe urge to defaecate†				
Longer than 1 h	50 (20.3)	30 (21.4)	13 (19.7)	0.85
No more than 1 h	69 (28.0)	38 (27.1)	20 (30.3)	
No more than 30 min	71 (28.9)	39 (27.9)	13 (19.7)	
No more than 15 min	39 (15.9)	20 (14.3)	14 (21.2)	
No more than 5 min	17 (6.9)	13 (9.3)	6 (9.1)	
Episodes of seepage (minor incontinence) per 24 h				
0 (i.e. never)	187 (36.7)	154 (42.2)	62 (37.8)	0.028
< 1 (i.e. not every day)	205 (40.2)	132 (36.2)	67 (40.8)	
1–2	57 (11.2)	44 (12.0)	21 (12.8)	
3–4	30 (5.9)	12 (3.3)	7 (4.3)	
> 4	31 (6.0)	23 (6.3)	7 (4.3)	
Episodes where unable to hold the stool (major incontinence) per 24 h				
0 (i.e. never)	373 (73)	275 (76.4)	104 (64.2)	0.04
< 1 (i.e. not every day)	97 (19)	71 (19.7)	44 (27.2)	
1–2	29 (5.7)	11 (3.0)	11 (6.8)	
3–4	10 (1.9)	2 (0.6)	2 (1.2)	
> 4	2 (0.4)	1 (0.3)	1 (0.6)	
Episodes of incomplete evacuation per 24 h				
0 (i.e. never)	112 (22.0)	92 (25.1)	35 (21.5)	0.44
< 1 (i.e. not every day)	182 (35.7)	139 (38)	60 (36.8)	
1–2	115 (22.5)	80 (21.9)	44 (27.0)	
3–4	52 (10.2)	30 (8.2)	14 (8.6)	
> 4	49 (9.6)	25 (6.8)	10 (6.1)	

Table 3 (Continued).

Variable	Interval from RPC			P
	0–10 years n (%)	11–20 years n (%)	21–30 years n (%)	
Pads, panty liners or similar				
Yes	132 (25.8)	98 (26.7)	62 (37.8) [†]	0.01
No	380 (74.2)	269 (73.3)	102 (62.2)	
Antidiarrhoeal medicine				
Yes	175 (34.4)	110 (30.1)	50 (30.5)	0.35
No	333 (65.6)	255 (69.9)	114 (69.5)	
Antibiotics for bowel problems				
Yes	49 (9.6)	26 (7.1)	10 (6.0)	0.242
No	461 (90.4)	340 (92.9)	154 (94.0)	

Not all returned questionnaires were filled out completely.

*,[†]Patients who responded that they have a sudden and severe urge to defaecate.

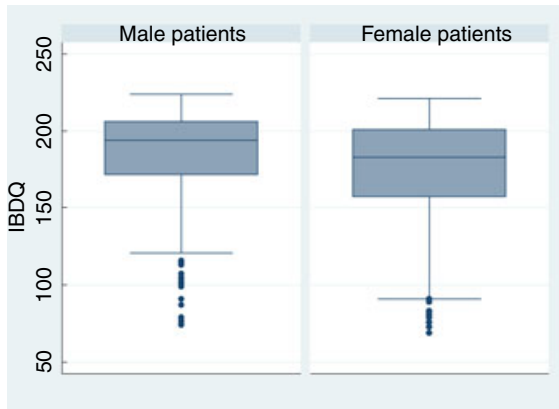


Figure 2 Box-and-whisker plots showing inflammatory bowel disease questionnaire (IBDQ) scores in male and female patients. The box displays the interquartile range (25th–75th percentiles). The whiskers display the upper and the lower values within 1.5 times the interquartile range. Comparison was performed using the Mann–Whitney *U*-test. $P < 0.001$.

The exclusion of pouch failures in this study is an inherent bias in the selection of the study population because we looked at patients with better-functioning pouches or patients who are able to tolerate worse-functioning pouches. However, in the literature, poor function is the cause of pouch failure in only 23% of patients and the bias is therefore limited [17].

In the present study, female patients were shown to have significantly more urgency, bowel movements and pad usage compared with male patients. There was no correlation between age and urgency for either sex. These gender differences are identical to the results of Rottoli *et al.* [18]. In a recent study they found the difference to be independent of whether the anastomoses were handsewn or stapled. Some studies describe a

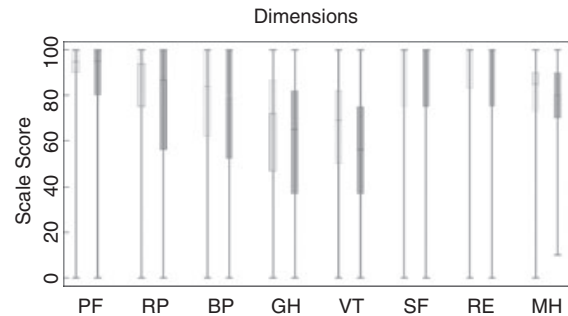


Figure 3 Box-and-whisker plots showing Short-Form 36 (SF36) results for male (□) and female (■) patients. The box displays the interquartile range (25th–75th percentile). The whiskers display the range. BP, body pain; GH, general health perception; MH, mental health; PF, physical functioning; RE, role limitations due to emotional problems; RP, role limitations due to physical problems; SF, social functioning; VT, energy and vitality.

significantly lower resting and squeeze pressure in female patients [19], which probably reflects a physiological difference in healthy, continent patients that could become clinically important in RPC patients. Despite small, but statistically significant, gender differences, it is important to note that the clinical relevance must be judged along with QoL. In our study this was also reduced among female patients.

As previously described, function has been shown to correlate significantly with QoL for patients having RPC. QoL is an important measure of surgical outcome because morbidity and mortality rates have decreased during the last few decades. We used generic (SF36) and condition-specific (IBDQ) questionnaires concurrently, as recommended in QoL studies [11,12].

The lower IBDQ score in female patients might be caused by a poorer bowel function. Other studies have also found a high QoL measured by IBDQ [11,12], but gender differences have, to our knowledge, not been described previously.

Häuser *et al.* [11] validated the German version of the IBDQ in patients with UC having RPC, but included only 61 patients. They found good acceptance, reliability, and convergent and discriminant validity, but limited face and construct validity. This could mean that a full assessment of disease-specific QoL is not obtained in RPC patients, and emphasizes the need to develop a disease-specific QoL questionnaire for RPC patients.

The higher SF36 score in male patients could be a reflection of better bowel function. Several studies have confirmed that generic QoL, measured using the SF36, is generally high in RPC patients [5,8,12,15]. Our results support these findings. Age at the time of RPC is considered a prognostic factor for pouch function, with worse results for older patients [20]. In our study, most patients were young with a median age of approximately 30 years at the time of RPC in all three groups.

In agreement with most studies, we found no difference between the frequency of defaecation according to the interval from RPC [5,16], with the majority occurring during the day, as also described by others [5,16,21]. Most of our patients had one or two nocturnal bowel movements, as in other studies [16,22]. The reported results of urgency are heterogeneous. We found that 14% of patients operated on 0–10 years previously had urgency defined as the inability to defer defaecation for more than 30 min. This is less than the value of 23% reported in another study of 291 patients with a median follow up of 15 years [8]. Lovegrove *et al.* [23] found that 12% of patients in one study suffered from urgency and 56% of patients in another study suffered from urgency 10 years after RPC [24], but did not define the symptom. Tekkis *et al.* described a frequency of 5.1% at 1 year after RPC, which had increased to 9% at 15 years, when urgency was defined as the inability to defer defaecation for more than 30 min [7]. The discrepancy between our study and others, regarding frequency, might be explained by various, or even no, definitions of the symptom, which makes comparison of the results difficult. We used a range of < 5 min to more than 1 h when describing urgency and could therefore adapt our definition of the symptom. It could be argued that 30 min is ample in modern-day society to find a toilet, and that inability to defer defaecation for no more than 15 min is a more appropriate definition of urgency. Overall, 7% of our patients fitted this definition. The majority had one to three episodes per day. Urgency

has been evaluated up to 28 years after RPC in a large follow-up study, where it was increased [7]. Another study also reported an increase of urge over time [25]. We found a significant reduction in the number of patients with urgency when patients operated on 0–10 years previously were compared with those operated on 11–20 years previously, but the cross-sectional design of our study does not allow any conclusions that differences in bowel function are caused by changes over time or different cohorts.

In previous studies, the frequency of major incontinence varied from 2 to 15% [21,26]. The differences between these studies may depend on the definition of major incontinence. We defined it as uncontrolled loss of stool and included patients who did not experience it regularly. We found that 27% overall had major incontinence at some time or other, but only 7% had it every day. Slightly better results were described in a large meta-analysis of more than 9000 RPC patients (for UC and familial adenomatous polyposis) where 3.7% regularly experienced major incontinence [26]. The increased frequency for patients operated on 21–30 years previously could be explained by a fall in sphincter pressure over time [16], but differences caused by the type of anastomosis or stapling technique cannot be excluded [9,16]. Seepage was defined as soiling/spotting on the underwear, and 22% of all patients experienced this every day. Similar results are described in another study [7].

A consequence of continence disturbance is the use of pads, which was 27% for patients operated on 11–20 years previously. Others found this to be 40–50% over a similar follow-up period [7,16]. In this study, patients were asked directly if use of pads was caused by bowel symptoms (and not urinary incontinence or vaginal secretion). This was rarely carried out in other studies, and could explain the large discrepancy between the results of the present study and those of others. The majority of the patients had a J-pouch reconstruction, although an S-pouch was used in the early period. Tekkis *et al.* [7] found no difference in seepage, incontinence and the use of pads between S and J pouches.

In summary, the present study is the first to include data representative of an entire nation. Its major findings included a greater incidence of urgency, bowel frequency and pad usage in female patients, which was associated with reduced QoL. However, in general, RPC conferred good function and there was a high degree of satisfaction with the operation.

Conflict of interest

None declared.

Author contribution

All authors have contributed to: conception and design of the study; generation, collection, assembly, analysis and/or interpretation of data; drafting or revision of the manuscript; approval of the final version of the manuscript.

Acknowledgements

Colitis and Crohn's Foundation of Denmark.

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Appendix I Diagnosis codes according to the International Classification of Diseases (ICD) 8–10.

45060	Total colectomy
45080	Rectocolectomy
45840	Resection of rectum
43785	Two loop (J-reservoir)
43786	Three loop (S-reservoir)
43890	Ileoanal reservoir
KJFH30	Colectomy/ileoanal anastomosis without ileostomy
KJFH33	Colectomy/ileoanal anastomosis with ileostomy
KJGB50	Mucosal proctectomy and ileoanal anastomosis
KJGB60	Excision of rectum and ileoanal anastomosis after colectomy
KJGB00	Resection of rectum
KJFH20	Proctocolectomy and ileostomy
KJFH10	Colectomy and ileostomy

Surgical procedure codes according to the Danish classification and NCSP.

56319	Ulcerative colitis
56399	Chronic enterocolitis
DK51_	Ulcerative colitis

All patients should have at least one code for surgical procedures and one code for diagnosis.
NCSP, Nordic Classification for Surgical Procedures.