ORIGINAL CONTRIBUTION

Long-term Results After Restorative Proctocolectomy With Ileal Pouch-Anal Anastomosis at a Young Age

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BACKGROUND: Restorative proctocolectomy with IPAA is an optimal surgical treatment for patients with familial adenomatous polyposis and therapy resistant ulcerative colitis, few data are available on long-term results in patients who have undergone this operation at a young age.

OBJECTIVE: The aim of this study was to investigate long-term functional outcome, quality of life, body image, and sexual function after restorative proctocolectomy with IPAA in young patients with familial adenomatous polyposis or ulcerative colitis.

DESIGN, SETTINGS, AND PATIENTS: The study consisted of a retrospective review of medical records and questionnaire follow-up of 26 consecutive patients with familial adenomatous polyposis or ulcerative colitis who had undergone surgery between January 1992 and October 2008 at the Maastricht University Medical Center, were aged 10 to 24 years at the time of surgery, and had at least 1 year of follow-up after surgery.

MAIN OUTCOME MEASURES: We reviewed medical records from an institutional database regarding surgical procedures and short- and long-term complications. At the end of 2009, validated questionnaires covering bowel function (Colorectal Functional Outcome Questionnaire), quality of life (Short Form-36 and Gastrointestinal Quality of Life Index), body image and cosmesis (Body Image Questionnaire), and sexual function (International Index of Erectile Function for men and Female Sexual Function Index for women) were mailed to patients.

RESULTS: Median age at surgery was 18 years, and median follow-up was 12.5 (range, 2–18) years. Long-term colorectal complications occurred in 23 patients (88%), and were directly related to the surgery in 20 patients (77%). Five patients needed pouch excision. The questionnaire response rate was 88%. Bowel function, quality-of-life, and body image and cosmesis scores were all lower in patients than in historical normal control populations. Men did not report impotence or retrograde ejaculation, but 50% of women reported sexual dysfunction.

LIMITATIONS: This was a retrospective study in a small number of patients from a single institution with no comparison groups.

CONCLUSIONS: Restorative proctocolectomy with IPAA can be performed in young patients with an acceptable functional outcome, but at the cost of relatively high complication rates, poor body image and cosmesis, and a high rate of sexual dysfunction in women. Because young patients undergoing this surgical procedure may experience negative long-term effects, surgeons should be aware of all potential consequences, inform patients as to

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what to expect, and ensure long-term follow-up to deal with long-term complications.

KEY WORDS: Ileal pouch-anal anastomosis; Young age; Long term; Bowel function; Quality of life; Body image; Sexual function.

Restorative proctocolectomy (RPC) with ileal pouch-anal anastomosis (IPAA) has emerged as a preferred surgical treatment for many patients with therapy-resistant ulcerative colitis or familial adenomatous polyposis.[1–4] Many studies addressing short-term results after RPC with IPAA in the adult population have found satisfactory levels of continence and stool frequency, as well as excellent quality of life.[5–8] Studies regarding body image and sexual function are rare, and available data show some contradictions.[7–10] Regarding bowel function and quality of life in young patients, only short-term results have been described, and these are consistent with results in adults.[3,11,12] Furthermore, only limited data are available regarding long-term functional outcome, quality of life, body image, and sexual function in patients who have undergone RPC with IPAA at a young age.[13]

In patients with ulcerative colitis or familial adenomatous polyposis, RPC with IPAA is often performed during adolescence, which is one of the most vulnerable periods in a person's maturation. We hypothesize that body image and sexual function can be impaired as a result of this intervention, lowering quality of life in this age group. We therefore performed a retrospective study to evaluate long-term functional outcome, quality of life, body image, and sexual function in patients with ulcerative colitis or familial adenomatous polyposis who had undergone RPC with IPAA at a young age.

PATIENTS AND METHODS

Patients

Consecutive patients who had undergone RPC with IPAA at the Maastricht University Medical Center (MUMC) from January 1992 through October 2008 were identified from medical records in the institution's electronic patient database. Patients were invited to participate in the study if they had a diagnosis of ulcerative colitis or familial adenomatous polyposis, were 10 to 24 years old at the time of the operation, were 18 years or older at the time of inclusion in the study, and had at least 1 year of follow-up after surgery.

The age range from 10 to 24 years was chosen according to the World Health Organization definition of "young people," which covers both patients defined as "adolescents" (10–19 years) and those defined as "youth" (15–24 years).[14] All patients had to be at least 18 years at the time of inclusion because the questionnaires used in the study have been validated only in this age group.

The medical ethics committee of the MUMC approved the study protocol, and all patients provided written informed consent.

Review of Medical Records

A retrospective chart review provided information about patient age at the time of surgery, indication for surgery (ulcerative colitis or familial adenomatous polyposis), preoperative medication, body mass index before surgery, operative setting (acute or elective), type of procedure (open or laparoscopic), stages of the procedure (1 or 2 stages), use of a diverting loop ileostomy, and complications (short-term and long-term). An acute operative setting was defined as no scheduled surgical procedure before hospitalization. Surgery was postponed (for a maximum period of 2 months) in some patients with familial adenomatous polyposis as a result of waiting lists. Short-term complications were defined as those occurring during the first 30 days after the operation, whereas any complication that occurred after 30 days was characterized as long-term.

Questionnaires

To assess long-term outcome of treatment, we sent a survey to patients by mail at the end of 2009. The survey included a letter with information on the study purpose and several questionnaires covering bowel function, quality of life, body image and cosmesis, and sexual functioning. If patients did not reply within 2 weeks, a reminder was sent. This study was performed by investigators not involved in the surgical management of the patients.

Bowel Function. Bowel function was evaluated using the Colorectal Functional Outcome (COREFO) questionnaire,[15] which consists of 27 questions and has been validated in Dutch.[15] This questionnaire assesses 5 categories: incontinence, social impact, frequency, stool-related aspects, and use of medication. Scores for each category range from 0 to 100, with higher scores representing increased impairment of bowel function. Furthermore, the COREFO questionnaire allows separate evaluation of daytime and nighttime stool frequency and soiling frequency.

Quality of Life. Overall quality of life was assessed by using the validated Short Form-36 Health Survey (SF-36).[16] The survey consists of 8 multi-item scales: physical functioning, role limitations due to physical problems, bodily pain, general health perception, vitality, social functioning, role limitations due to emotional problems, and mental health. Based on these subscales, summary scores for the physical component and the mental component can be calculated. The scales all range from 0 to 100. A higher score indicates higher well-being.

The Gastrointestinal Quality of Life Index (GIQLI) was also used. This is a validated instrument measuring quality of

life related to the gastrointestinal tract.[17] This questionnaire contains 36 questions, subdivided into 4 response categories: symptoms (score ranging from 0 to 76), physical status (0 to 28), emotions (0 to 20), and social dysfunction (0 to 20). A total score can be calculated, ranging from 0 to 144. A higher score represents a better quality of life.

Body Image and Cosmesis. The Body Image Questionnaire (BIQ) described by Dunker et al[18] was used to evaluate body image and cosmesis. This 8-item questionnaire can be divided into a body image scale and a cosmesis scale. The body image scale evaluates patients' feelings about their own body. This scale ranges from 5 (lowest body image score) to 20 (highest body image score). The cosmesis scale consists of 3 questions to determine patients' level of satisfaction with the physical appearance of the scar after surgery. Combining the scores of the 3 questions results in a cosmesis score ranging from 3 (lowest satisfaction) to 24 (highest satisfaction).[7,8,18]

Sexual Function. The International Index of Erectile Function (IIEF) is a 15-item questionnaire developed and validated as a scale for assessing male sexual function.[19] The questionnaire assesses 5 domains: erectile function (1 to 30), orgasmic function (0 to 10), sexual desire (2 to 10), intercourse satisfaction (0 to 15), and overall satisfaction (2 to 10). The IIEF total score ranges from 5 to 75. Based on a study describing male sexual functioning after surgery for rectal cancer, we considered a value below 42.9 to signify sexual dysfunction.[20]

The Female Sexual Function Index (FSFI) is a 19-item validated questionnaire for evaluating female sexual function. The questionnaire consists of 6 domains: desire (1.2 to 6), arousal (0 to 6), lubrication (0 to 6), orgasm (0 to 6), satisfaction (0.8 to 6), and pain (0 to 6). The FSFI total score ranges from 2 to 36. A score below 26 implies that women are experiencing sexual dysfunction.[21]

Statistical Analysis

Descriptive data were reported as mean with SD or median with range, as appropriate. Dichotomous variables were compared by means of the Fisher exact test. Differences between groups were analyzed with the Mann-Whitney *U* test. Correlation coefficients were calculated for quality of life, body image, and sexual function scores by using Spearman correlation. A p value below 0.05 was considered statistically significant. Data were analyzed using SPSS software (version 15.0 for Windows, IBM/SPSS).

RESULTS

Patient Characteristics

A total of 26 patients were eligible for participation in this study. No patients who met the age criteria (10 to 24 years) at the time of the operation had to be excluded for not meeting the age requirement (18 or older) at the time of inclusion in our study.

The response rate for the questionnaires was 88% (23 patients), with 1 written reminder. The median follow-up time after construction of the IPAA was 12.5 (range, 2–18) years. Other patient characteristics are given in Table 1. Table 2 shows details regarding the surgical procedure.

TABLE 1. Characteristics of 26 patients who underwent restorative proctocolectomy

Gender, n (%)	
Male	11 (42)
Female	15 (58)
Indication for operation, n (%)	
FAP	10 (38)
Ulcerative colitis	16 (62)
Age (y), median (range)	
At operation	18 (12–23)
At last follow-up	29.5 (21–40)
Follow-up (y), median (range)	12.5 (2–18)
BMI, median (range)[a]	
Preoperative	20.1 (13.3–27.5)
At last follow-up	22.0 (17.8–32.0)
Preoperative medication, n (%)	
Steroids	7 (27)
Immunosuppressive agents	1 (4)
Immunosuppressive agents and steroids	8 (31)
None	10 (38)

FAP = familial adenomatous polyposis.
[a]Preoperative BMI was corrected for age in patients younger than 21 years.

Complications

Short-term Complications. There was no mortality in this study. Of the 26 patients, 13 patients (50%) had a total of 17 short-term colorectal complications (Table 3), including anastomotic leakage, recurring hemorrhage, ileus, pelvic abscess, enteric fistula, wound infection, and pouchitis. Within 30 days, 10 patients (38.5%) needed 1 to 5 surgical reinterventions each, because of pelvic abscess, hemorrhage, anastomotic leakage, ileus, or revision of the pouch with construction of a temporary diverting ileostomy.

TABLE 2. Characteristics of the surgical procedure (n = 26)

Variable	*n (%)*
Surgical strategy	
Open	23 (88)
Laparoscopic	3 (12)
Surgical setting	
Acute	10 (38)
Elective	16 (62)
Number of stages	
1	16 (62)
2	10 (38)
Protective ileostomy	9 (35)
Mucosectomy	17 (65)

TABLE 3. Short-term (<30 days) complications after restorative proctocolectomy with IPAA in 26 young patients

Complication	*n (%)*
Colorectal	
Total number of complications per patient	
0	13 (50)
1	10 (38)
2	2 (8)
3	1 (4)
Type and management	
Anastomotic leakage	2 (8)
Recurring hemorrhage	4 (15)
Ileus	2 (8)
Operative management	2 (8)
Conservative management	0 (0)
Pelvic abscess	5 (19)
Operative management	3 (12)
Conservative management	2 (8)
Enteric fistula	2 (8)
Operative management	2 (8)
Conservative management	0 (0)
Wound infection	1 (4)
Pouchitis	1 (4)
Total number of reoperations per patient	
0	16 (61.5)
1	8 (30.8)
1–5	2 (7.7)
Other complications	
Pneumothorax	2 (8)

TABLE 4. Long-term (>30 days) complications after restorative proctocolectomy with IPAA in 26 young patients

Complication	*n (%)*
Colorectal	
Total number per patient	
0	3 (12)
1	10 (38.5)
2	6 (23)
3	2 (8)
4	4 (15)
5	0 (0)
6	1 (4)
Type and management	
Pelvic abscess	9 (35)
Operative management	3 (12)
Conservative management	6 (23)
Ileus	14 (54)
Operative management	9 (35)
Conservative management	5 (19)
Enteric fistula	5 (19)
Operative management	5 (19)
Conservative management	0 (0)
Pouchitis	17 (65)
Cicatricial hernia	5 (19)
Total number of reoperations per patient	
0	13 (50)
1	8 (31)
2–10	5 (19)
Pouch removal with permanent ileostomy	5 (19)
Other complications	
Pulmonary embolism	3 (12)

Revision of the pouch was needed in 2 patients because of anastomotic leakage and a pouch-vaginal fistula. Other complications could be managed conservatively.

Long-term Complications. Of the 26 patients, 23 (88%) had a total of 50 long-term colorectal complications, including pelvic abscess, ileus, enteric fistula, pouchitis, and cicatricial hernia (Table 4). In 20 patients (77%), the colorectal complications were directly related to surgery. In 3 patients, the only long-term complication was pouchitis, which was not directly related to the surgical procedure.

The most common long-term complication was pouchitis; 17 patients (65%) had 1 episode or more. Pouchitis was found significantly more often in patients with ulcerative colitis than in patients with familial adenomatous polyposis ($p < 0.01$). Other complications were not significantly different between these 2 groups, although the total number of complications was significantly higher in patients with ulcerative colitis ($p = 0.029$).

A total of 13 patients (50%) needed 1 to 10 reoperations for late complications (Table 4). Pouch revision with a temporary diverting ileostomy was necessary in 6 patients. Indications for pouch revision included fistula formation in 4 patients, insufficient pouch function in 1 patient, and an unknown indication in 1 patient. Eventually, 5 patients (19%) were unable to preserve their pouch because of therapy-resistant pouchitis, recurring fistula, and dysfunctional pouch. They all underwent operative removal of the pouch and construction of a permanent ileostomy. The number of complications and number of reoperations were not correlated with duration of follow-up.

Bowel Function

Because the COREFO questionnaire measures pouch function, the 5 patients with an end ileostomy were excluded from the analysis of bowel function. In the remaining 18 patients, mean scores on the COREFO subscales were as follows: incontinence, 21.8 (SD, 20.0); social impact, 24.8 (SD, 24.9); frequency, 39.6 (SD, 20.7); stool-related aspects, 23.6 (SD, 24.5); medication, 16.2 (SD, 23.3); and total score, 23.8 (SD, 20.5). The median defecation frequency was 5 to 7 times during daytime and 1 to 2 times during nighttime. Six patients (33%) were not always able to withhold their stool for more than 15 minutes. Incontinence for solid stool was reported in 3 patients (17%) during daytime and 4 patients (22%) during nighttime, to a maximum of 3 to 5 times per week. Some degree of daytime soiling occurred in 8 patients (44%), and nighttime soiling in 11 patients (61%). Seven patients (39%) had to wear an incontinence pad 7 days per week. To summarize stool continence, 7 of 18 patients (39%) were fully continent without any degree of soiling. Bowel function was clearly correlated with total number of short- and long-term complications ($r < 0.743$; $p < 0.038$).

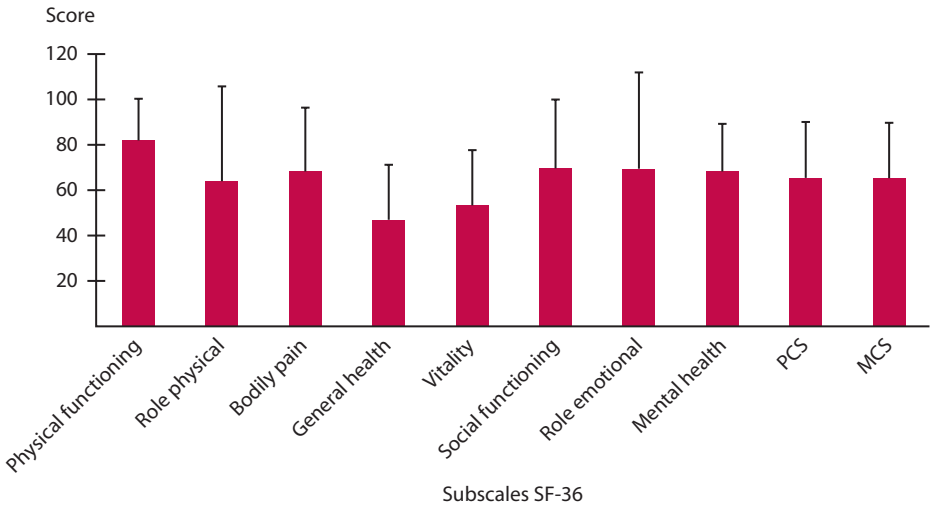

FIGURE 1. Quality of life assessed with the SF-36 questionnaire in young patients after proctocolectomy with IPAA. Minimum score is 0, maximum score is 100. A higher score indicates higher well-being. Values are means with SD. (PCS = physical component summary, MCS = mental component summary).

Quality of Life

Regarding overall quality of life as measured by the SF-36, the mean score for the physical component summary (PCS) was 66 (SD, 25), and the mean for the mental component summary (MCS) was 65 (SD, 24) (Fig. 1). Quality of life related to the gastrointestinal tract, as measured with the GIQLI, showed a mean total score of 104 (SD, 27) (Fig. 2). The GIQLI total score correlated positively with both the PCS ($r = 0.89$; $p < 0.001$) and the MCS ($r = 0.81$; $p < 0.001$). Impairment of bowel function measured by means of the COREFO total score correlated negatively with all measures of quality of life (PCS, $r = -0.655$, $p = 0.001$; MCS, $r = -0.607$, $p = 0.002$; and GIQLI total score, $r = -0.441$; $p = 0.035$). No significant correlations were found between the SF-36 subscales and diagnosis, number of complications, or number of reoperations.

Body Image and Cosmesis

Male patients reported higher mean body image scores than female patients, although the difference was not significant: mean, 16.3 (SD 3.1) vs 13.5 (SD 4.1); $p = 0.08$. Moreover, cosmesis scores were higher for men than for women, although this difference was also not significant: 15.2 (SD, 5.5) vs 10.7 (SD 4.4); $p = 0.07$. No differences in body image or cosmesis were found regarding the number of stages, surgical procedures, or having a permanent ileostomy ($p > 0.05$). Additionally, body image and cosmesis did not correlate significantly with each other ($r = 0.379$; $p = 0.074$). No significant correlations were observed between body image and any of the measures of quality of life, including PCS, MCS, and GIQLI total score (all, $r < 0.413$; $p > 0.050$).

Sexual Function

Complete responses were given by 10 male patients for the IIEF questionnaire and by 13 female patients for the FSFI (Table 5). Because each of these questionnaires covers several different domains, every patient was able to answer at least a part of the questionnaire. However, it was possible to calculate a total score only for patients who were sexually active with a partner.

All of the men had total scores above 42.9, indicating that they had no sexual dysfunction. Furthermore, no patient was impotent and no retrograde ejaculation was reported. In contrast, 50% of the women who answered all 19 items of the FSFI had a total score lower than 26, indicating sexual dysfunction. Stool frequency and permanent ileostomy were not associated with low scores for female sexual function ($p > 0.05$). However, sexual dysfunction in women was significantly correlated with long-term complications ($r = 0.708$; $p = 0.05$). Neither male nor female sexual function was significantly correlated with quality of life (PCS, MCS, and GIQLI total scores, $r < 0.703$; $p > 0.078$) or with body image and cosmesis ($r < 0.610$; $p > 0.108$).

DISCUSSION

Many surgeons consider RPC with IPAA to be the best available operative strategy for young patients with severe ulcerative colitis and familial adenomatous polyposis. Young people undergoing this operation are at a vulnerable period in their lives, in which long-term relationships are established and career plans are made. Therefore, it is important to minimize the effects of the surgical procedure on normal life. In addition to assessing postoperative morbidity and mortality, it is also important to assess postoperative quality of life, body image, and sexual function to evaluate the success of a surgical technique. This study is among the first to evaluate long-term effects on these endpoints in patients who undergo RPC with IPAA at a young age (10–24 years).

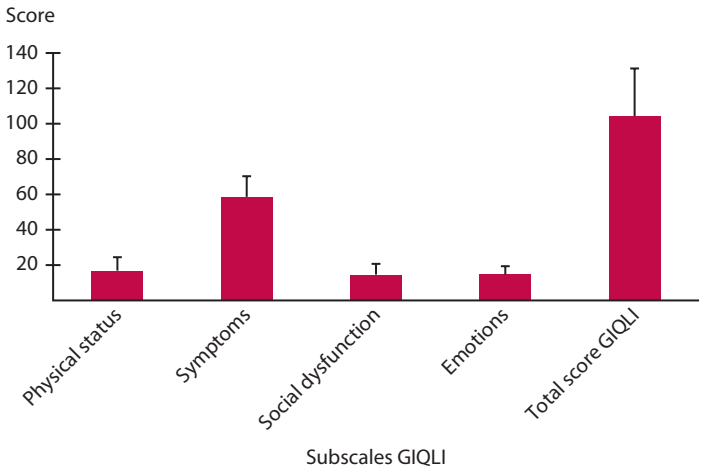

FIGURE 2. Results of the Gastrointestinal Quality of Life Index (GIQLI) in young patients after proctocolectomy with IPAA. Minimum score is 0, maximum score is 144. A higher score indicates better quality of life. Values are means with SD.

The study showed that the number of postoperative complications was related to long-term bowel function and to long-term sexual function in women. Therefore, the goal of optimizing long-term outcome should involve reducing the number of complications, both short-term and long-term. In our population, the rate of short-term complications (50%) was relatively high compared with 19% to 41% in earlier published data.[4,22,23] Centers with fewer or minor short-term complications may have better long-term results. Long-term complications occurred in 88% of our patients, and reoperations were performed in 50%. This is a relatively high number, but recent published data by Pakarinen et al[13] were in accordance with these results. Their study included a comparably young group with a mean follow-up of 10 years and showed rates of 75% for surgical complications and 54% for reoperations. However, earlier published data with shorter duration of follow-up (ranging from 3.7 to 5.4 years) showed lower complication rates varying from 28% to 54%.[4,12,23,24] These differences might be explained by the increased risk of adhesive bowel obstruction that occurs after a prolonged duration of follow-up. Furthermore, earlier published data included only severe cases of pouchitis. In contrast, the present study included every level of pouchitis, which may have led to inclusion of a higher number of complications.

TABLE 5. Sexual function male and female patients after proctocolectomy with IPAA

Scale	*Mean score (95% CI)*
Men (n = 10), IIEF	
Erectile function (n = 8)	28.9 (27.4–30.3)
Orgasmic function (n = 8)	10.0 (–)
Sexual desire (n = 10)	7.0 (5.5–8.6)
Intercourse satisfaction (n = 7)	12.9 (10.9–14.8)
Overall sexual satisfaction (n = 10)	7.0 (4.5–9.5)
Total IIEF score (n = 7)	68.4 (65.3–71.6)
Women (n = 13), FSFI	
Sexual desire (n = 12)	3.0 (2.3–3.7)
Sexual arousal (n = 9)	3.8 (2.5–5.1)
Lubrication (n = 9)	4.1 (2.7–5.5)
Orgasmic function (n = 11)	4.0 (3.0–5.1)
Sexual satisfaction (n = 11)	4.7 (3.6–5.8)
Sexual pain (n = 10)	4.4 (3.1–5.8)
Total FSFI score (n = 8)	24.2 (17.6–30.8)

IIEF = International Erectile Function Index; FSFI = Female Sexual Function Index; n = number of patients responding.

Pouch surgery aims to achieve an average of 5 to 6 bowel movements per day and complete continence without nighttime evacuation.[25] Although this would be optimal, other studies found that both young patients[11–13] and adults[25–29] experienced at least 1 bowel movement at night in addition to 5 to 6 bowel movements per day, and 31% to 56% had soiling. These results were consistent with the results on the COREFO bowel function questionnaire in our population, which showed an acceptable bowel function almost reaching the target values stated in previous articles.[25–29] However, our patients had substantially lower COREFO scores than those reported in earlier publications for patients without complaints.[14]

Another recently described phenomenon may influence bowel function. A review by Chambers et al[30] showed that in pouch surgery, mucosectomy with a handsewn anastomosis leads to poorer function than a stapled anastomoses. Of the patients described in this report, 65% underwent a mucosectomy. In contrast, in our current practice we use double-stapled anastomosis without mucosectomy in most patients, although an operation technique that does not include mucosectomy may involve a higher risk of dysplasia and inflammation.[27] Nevertheless, future results may show better bowel function due to this change of technique.

The SF-36 quality-of-life scores in our patients appeared to be lower on all subscales than those of a normal

Dutch population in the age group from 16 through 40 years.[16] We were obliged to use this adult population for comparison because we found no studies using the SF-36 in young patients. Several studies have evaluated long-term quality of life using the SF-36 in adult patients after RPC with IPAA. Most concluded that quality of life was good to excellent in adult patients, which was comparable to quality of life in the general population.[26,29,31] However, a report by van Duijvendijk et al[32] found lower quality-of-life scores compared to the normal age-matched population. The study population in that report had a lower mean age at the time of surgery (30 years) than that in earlier published data. The authors proposed that the lower quality-of-life scores in their patients might be explained by a greater impact of RPC with IPAA in this young developing age group than in the adult population.[32] They even suggested that this finding might be an argument for postponing operation in young patients with mild disease. Because they may have fewer coping strategies than adults, younger patients are often more vulnerable to certain life events or situations, and therefore both physical and psychological changes can be more drastic in this age group. Such factors may explain the findings of lower quality-of-life scores in our study population, as our patients were even younger than those in the study by van Duijvendijk et al.

Previous studies evaluating body image and cosmesis have reported significant differences between open and laparoscopic approaches with regard to cosmesis.[7,8] In our study population, only 3 of the 26 patients were operated laparoscopically. For that reason, we compared our results regarding body image and cosmesis with the patients from previous studies who had undergone conventional open surgery. Our male and female patients had lower body image and cosmesis scores than those in the Dunker et al study.[7] Polle et al[8] found lower body image scores in women than in men, whereas we did not see a significant difference between the sexes regarding body image and cosmesis. A gender difference would not be surprising, assuming that men set less value on their physical appearance.

Social and sexual contacts develop during maturation. Therefore it is imperative that the surgical procedure for ulcerative colitis and familial adenomatous polyposis does not interfere with this process. Nevertheless, sexual dysfunction after this operation is a well-recognized problem. Most studies report adequate sexual functioning after a relatively short postoperative follow-up period in patients who undergo the operation during adulthood.[6,33–35] To our knowledge, the present study is the first to use validated instruments to assess long-term sexual function after RPC with IPAA in young patients. Male patients in our study scored very well on all IIEF subscales. Similar findings have also been reported in other studies that have used this instrument.[6,9,35] Furthermore, although rates of erectile dysfunction and retrograde ejaculation assessed with non-validated instruments range from 0% to 25% after surgery for IBD,[33] none of the men in our study experienced erectile dysfunction or retrograde ejaculation. Male patients from this study scored better on all IIEF subscales compared with healthy controls.[19]

High rates of dyspareunia after IPAA, varying from 22% to 30%, have been reported in female patients.[34,36] Half of the women in our study reported long-term sexual dysfunction. This high percentage has also been reported by others using the FSFI questionnaire.[10,35] Because not all women filled in the whole questionnaire (mostly because of misinterpretation of the definitions), our results may be either an overestimation or an underestimation on this subject. Compared with a Dutch healthy control group, our female IPAA patients scored worse on almost every FSFI subscale.[37] Contrary to the high degree of female sexual dysfunction in our study sample, most of our female patients reported being satisfied with their sexual life after RPC with IPAA. These results are in line with earlier published data[33–36] and may be explained by the phenomenon called "response shift," which has also been described in cancer patients.[38] It means that long-term survivors develop a more positive appreciation of their sexual life.

In our study, bowel function correlated negatively with health-related and gastrointestinal quality of life. In contrast to our expectation, quality of life was not significantly correlated with diagnosis, number of complications, number of reoperations, body image, cosmesis, or sexual function.

We note that the most important limitations of our study are its small sample size (n = 26) and retrospective nature. Because of the small sample size, it was not possible to know whether lack of statistical significance meant lack of a true difference, there was insufficient power to detect true differences if they existed. Furthermore, this was a single-center study, and results from one hospital may not be generalizable to a general surgical population. Although our results are based on validated questionnaires, the retrospective nature of the study may have affected the patients' responses, particularly in regard to quality of life. Finally, we were not able to evaluate the differences between open and laparoscopic surgery in this young age group because of the small number of laparoscopic procedures. In the future, laparoscopic surgery may result in better outcomes in terms of quality of life, body image, cosmesis, and sexual function.

In the future, a larger patient population should be studied to draw further conclusions and possibly confirm the findings of this study. It would also be interesting to look at differences between young people and adults both in a healthy population and in an affected patient population to investigate whether a young age of patients at the time of surgery does indeed greatly influence long-term outcome.

For patients with familial adenomatous polyposis or ulcerative colitis, surgery is often the only treatment option, either because of an increased risk of cancer or as a result of severe illness. In such cases, despite the potential negative effects of surgery, it may the highest attainable quality of life. Quality of life and bowel function are also often imperfect with medical treatment. Even in patients whose disease can be adequately managed with medical therapy, surgery may provide a net benefit when negative effects of medical treatment (for example, growth suppression, hypertension, and osteoporosis in ulcerative colitis) are taken into account. Therefore, it is important for surgeons and other health professionals to be aware of the possible consequences of each procedure in young patients, to provide them with correct information about the benefits and risks of available treatment strategies, and to ensure long-term follow-up.

CONCLUSIONS

Restorative proctocolectomy with IPAA can be performed in young patients with an acceptable functional outcome, but at the cost of relatively high postoperative complication rates, poor body image and cosmesis, and a high rate of sexual dysfunction in women. Because young patients undergoing this surgical procedure may experience negative long-term effects, surgeons should be aware of all consequences and inform patients as to what to expect, and ensure long-term follow-up to deal with long-term complications. Nevertheless it must be considered that for some patients surgery is inevitable. Further research with a young patient population is necessary to determine whether age at surgery does indeed greatly influence long-term results.

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