



Original research

Self reported experience of sexual function and quality after abdominoperineal excision in a prospective cohort

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HIGHLIGHTS

- Sexual function is impaired after rectal cancer surgery.
- This study adds information on the bother perceived by patients with sexual impairment after rectal cancer surgery.
- This study also confirms previous data that patients do not feel adequately informed about possible sexual impairment.
- We have shown that men are more bothered by their sexual impairment than women.

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ABSTRACT

Introduction: Rectal cancer treatment, especially abdominoperineal excision (APE), can cause sexual dysfunction. There are indications that pre-operative information regarding sexual dysfunction is inadequate. The aim of this study was to explore self reported sexual function in a group of patients operated with APE and the patients' remembrance of preoperative information more than one year after their surgical procedure. **Methods:** Consecutive patients with rectal cancer operated with APE in one institution between 2004 and 2009 were included. Data was collected from hospital records and the Swedish Colorectal cancer registry. A detailed questionnaire was sent out to the patients 13–84 months post-operatively. **Results:** One hundred and eight patients were alive in February 2011, 84 agreed to participate and 89% returned the questionnaire. Men and women did not differ regarding age, tumour stage, neoadjuvant treatment or type of surgical procedure. More men were involved in a relationship; men had more thoughts about sex, were less satisfied and were more bothered than women by their sexual dysfunction. A majority of patients did not retain sufficient knowledge from the preoperative information regarding sexual dysfunction. **Discussion:** This exploratory study shows that although sexual activity was similar between the two genders, men reported more bother by their self-reported sexual dysfunction after an APE than women did. However, both men and women felt that the preoperative information was inadequate. **Conclusion:** Surgeons should focus more on information about the risk of sexual dysfunction as well as on its treatment at follow-up.

Trial registration: : ClinicalTrials.gov, NCT01323166.

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1. Introduction

Rectal cancer is a common disease, occurring mainly in patients around the age of 70 and a little more often in men. Treatment with the aim to cure involves surgery, and in many cases radio- and/or chemotherapy [1,2] Low tumours, less than 6 cm from the anal

verge, are often operated by an abdominoperineal excision (APE) with a permanent stoma.

One long-term complication after rectal cancer surgery is sexual dysfunction [3]. It is common after abdominoperineal excision [3–5] and may be aggravated by preoperative radiotherapy although this is debated [6–8]. Male sexual dysfunction is common, affecting both erection and orgasm [3] [8,9]. Female sexual dysfunction after rectal cancer surgery has been less studied than male sexual dysfunction [10], but there are indications of a substantial effect on sexual function such as loss of orgasm,

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dyspareunia and loss of lubrication [3,11,12]. However, it has been reported that the bother of sexual dysfunction differs between men and women [4]. Possible confounding factors when assessing sexual function and quality of sexual health are depression [13–15], impaired bowel function or the presence of a stoma [3,10]. There are several known instruments to assess sexual function, but the commonly used instruments from EORTC do not in detail investigate the sexual function, including but four questions. Other, more detailed, questionnaires such as the Female Sexual Function Index (FSFI) and the International Index of Erectile Function (IIEF) have been developed [16,17]. These questionnaires are not cancer specific, rendering comparisons with healthy subjects possible. The IIEF has been used in rectal cancer survivors [18] and the FSFI has been used in cancer survivors, although not rectal cancer patients [19], but the results have not been related to depression or total quality of life. The FSFI has also been used to assess sexual function prior to rectal cancer treatment [20,21], with results indicating that women have sexual inactivity and dysfunction prior to treatment.

Whether preoperative information is of importance for the experience of sexual dysfunction after rectal cancer surgery is not known, but lack such information has been documented in several studies [3,22], as well as the fact that patients may not retain information given [23]. Studies also indicate that treatment for sexual dysfunction can be improved [3].

The aim of this explorative study was to describe sexual function as well as perceived quality of sexual health after APE for rectal cancer among patients at least one year after their rectal cancer treatment. Another aim was to explore the remembrance of preoperative information as well as postoperative assistance for sexual dysfunction and compare the findings in men and women.

2. Methods

2.1. Study design

2.1.1. Patients

All patients operated at our institution with an abdominoperineal excision between 2004 and 2009 were identified from hospital records and the Swedish Colorectal Cancer Registry. The patient cohort has been described in depth previously [24] and the stoma function has been evaluated [25]. Patients with rectal cancer recurrence, palliative procedures and cases with other diagnoses than adenocarcinoma were excluded. For this study of self-reported health and quality of life, patients lost to follow-up and patients no longer alive at the start of the study were excluded.

After an introductory letter and a telephone call, all patients alive in the spring of 2011 agreeing to participate in the study were mailed the questionnaire. All patients received a reminder and thank you note after two weeks and if the questionnaire was not returned, a second phone call as a reminder.

2.1.2. Clinical data from charts and the Swedish Rectal Cancer Registry

Patient charts and the Swedish Colorectal Cancer Registry were reviewed for gender, age, BMI, preoperative adjuvant treatment, laparoscopic or open procedure, type of surgery (standard or extralevator APE), perioperative blood loss, operating time (including, when applicable, the turning of the patient), perioperative bowel perforation, American Society of Anaesthesiology (ASA)-classification as a surrogate marker for preoperative morbidity, tumour height, tumour stage (UICC), length of hospital stay and local recurrence.

2.1.3. Questionnaire regarding sexual function and quality of sexual life

The whole questionnaire on health related quality of life included 249 questions covering socioeconomic background, feeling of well-being and overall quality of life as well as questions regarding urinary, sexual and stoma function. It was developed using well-validated and previously described methods [26,27]. All questions have not been analysed for this report, the questions regarding stoma function, have been analysed and published previously [25]. All questions regarding sexual function and quality of sexual health were included in this analysis. As other studies have reported that quality of life and depression may affect or be affected by sexual dysfunction and poor quality of sexual health [3,10,13–15,28], questions on general physical and psychological function as well as depression were analysed as well.

The questionnaire was developed using in-depth qualitative interviews as a base together with previously validated questions on sexual function for both men and women [29,30], and an expert panel consisting of colorectal surgeons, oncologists, gynaecologists, nurses specialized in surgery then performed a content validation. The questionnaire was face-to-face validated by rectal cancer patients operated with abdominoperineal excision using the validation methods described previously for a questionnaire for prostate cancer patients [30]. The time frame in most of the questions was set to “the last month” to achieve as true answers as possible, except regarding the ability to achieve orgasm or erection and fear of embarrassment related to the stoma, where the time frame was set to “after surgery for your rectal cancer” to ascertain that dysfunction or problems would be reported even if patients had been sexually inactive within the last month. When asked about orgasm or erection patients also had the option to answer: “Not applicable, I could not reach orgasm/have an erection prior to surgery”.

When appropriate, patients were asked about the quality, frequency and intensity of a symptom as well as the corresponding bother [27]. All questions including quality, frequency and intensity of sexual function/activities included the alternative: “Not applicable, I have not had any sexual activity/been sexually aroused within the last month” and some questions also included “I don’t know” as an option.

Psychological symptoms, well being, and the subjective quality of life were assessed in an ordinal seven-point Likert-type response format. The patients indicated one of seven numbers on a line anchored by, for example, “no psychological well-being” and “the best possible psychological well-being”. Depression was evaluated with one single question with the answer options “yes”, “no” and “I don’t know”. This question has been found to correlate well to established depression scales [31].

2.1.4. Outcome variables

Psychological symptoms were assessed by a total of eight variables as described by Steineck et al. [30] together with the single question on depression described above.

Sexual function was evaluated with nine questions regarding sexual function in men and women; some questions were only applicable to one sex. Sexual health was defined as thoughts, bother and satisfaction regarding the patient’s sexual function and activity.

Information on sexual effects of APE was evaluated using one question on whether the patient was prepared for sexual impairment.

2.1.5. Surgical procedure

During 2004–2006, the perineal part of the APE was performed with the patient in the lithotomy position at our institution. This

“standard” technique (S-APE) was then replaced by the extralevator APE (E-APE) in 2006 and generally employed during the rest of the study period, regardless of tumour stage. Equal care was taken to preserve nerves in both groups during the abdominal part of the procedure.

2.1.6. Follow-up

All patients were contacted in the spring of 2011, rendering a median follow-up time after surgery of 45 (13–84) months.

2.1.7. Statistical analysis

The statistical analyses were performed with SPSS 19.0 (SPSS Inc., Chicago, Illinois, U.S.A.). Non-parametric testing was performed, as the data was not normally distributed. Chi-square test, Fisher's Exact Test and the Mann-Whitney-U analysis were used. Results are presented as median values with minimum and maximum range or percentages in parenthesis. Some of the data was dichotomized to distinguish presence of symptoms from no

symptoms. Symptoms were also related to the corresponding bother using the Chi-square test. When analysing questions regarding function during sexual activity the last month, only results from patients reporting sexual activity were included.

To evaluate potential selection bias, a comparison between the primary patient cohort and the study population was made.

Psychological symptoms were dichotomized using previously reported cut-off values [29,30].

2.1.8. Ethical aspects

The local ethics committee approved the study (#407-10) and the study was registered at ClinicalTrials.gov, NCT01323166.

3. Results

Out of 213 consecutive cases of APE, 108 patients were eligible for the study. A total 84 patients agreed to participate in the study and 75 patients (89%) returned the questionnaire (Fig. 1).

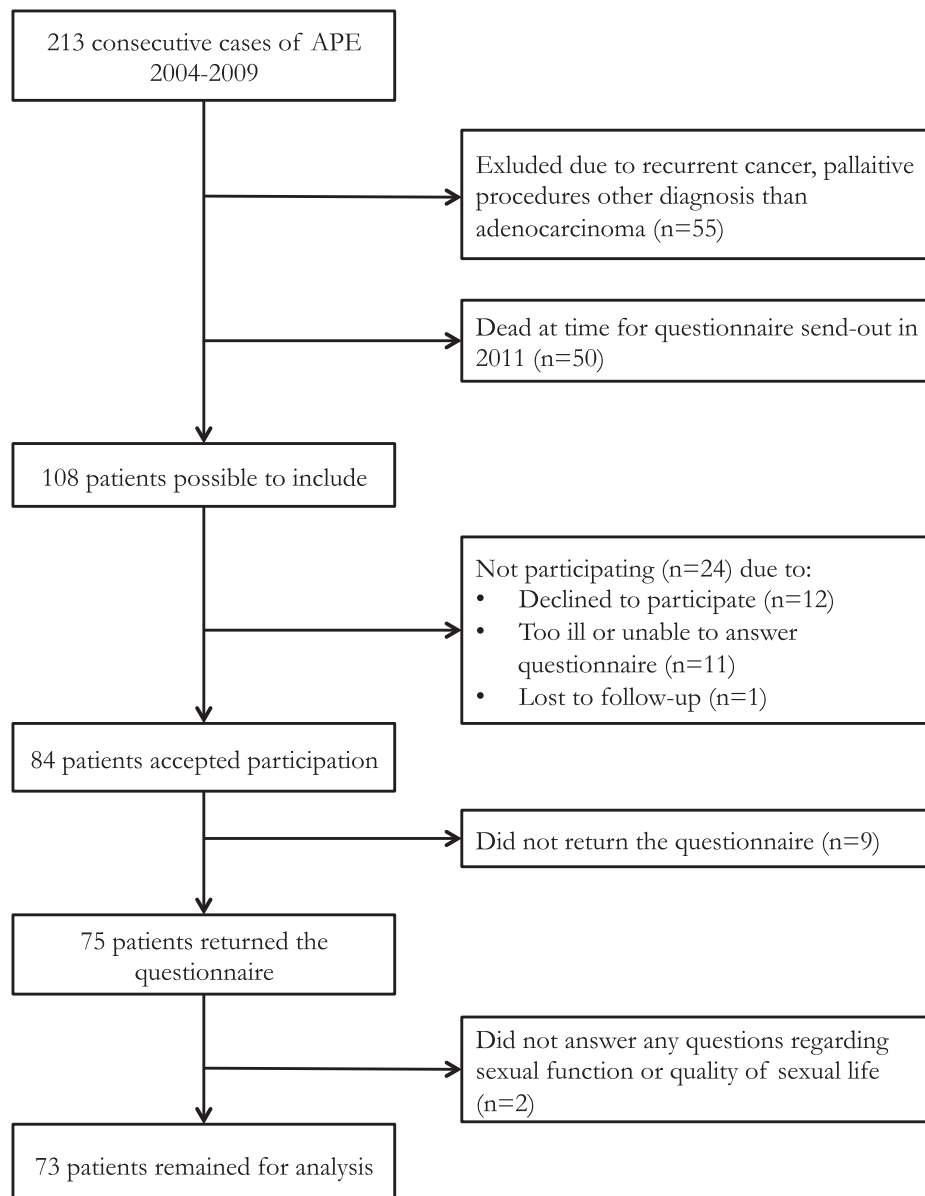


Fig. 1. Flowchart of patients.

All patients answering the questionnaire ($n = 75$) were compared regarding age, gender, type of surgery (standard or extralevator APE), tumour stage, ASA-classification, BMI and preoperative radiotherapy with patients not able or willing to participate in the study, patients lost to follow-up and patients dead during follow-up ($n = 83$). The patients in the study population ($n = 75$) had lower tumour stage and less severe co-morbidity (indicated by ASA-classification at index surgery) compared to patients not possible to include ($n = 83$), otherwise the groups were comparable.

Two male patients, aged 61 and 80 refrained from answering any of the questions regarding sexual function and quality of sexual health and were thus excluded from further analysis.

The baseline characteristics of the population are displayed in Table 1. There were no differences between male and female patients. Socioeconomic demography is displayed in Table 2. A majority of patients were living in an urban environment. More men than women were living in a relationship ($p < 0.05$). The educational level was diverse and a majority of the patients were retired prior to their surgery for rectal cancer.

3.1. Psychological symptoms

All eight psychological and physical variables are presented in Table 3. Female patients reported to a larger extent a low general physical ability than men ($p < 0.05$). The majority of both men and women did not regard themselves as depressed.

3.2. Sexual activity

Out of 73 answering patients, 7/29 (24%) women and 11/44 (25%) men had been sexually active within the last month. All of

Table 1
Baseline characteristics.

| | Men | Female |
|---|-----------------------|-----------------------|
| Patients (n) | 44 | 29 |
| Age at surgery (median) | 65 (35–88) | 68 (35–89) |
| BMI (median) ^a | 24 (20–37) | 23 (19–33) |
| Type of surgical procedure | | |
| Standard APE | 22 (50%) | 11 (38%) |
| Extended APE | 22 (50%) | 18 (62%) |
| ASA-classification | | |
| ASA I | 13 (30%) | 8 (28%) |
| ASA II | 26 (59%) | 18 (62%) |
| ASA III | 4 (9%) | 3 (10%) |
| ASA IV | 1 (2%) | 0 (0%) |
| Tumour stage (according to International Union Against Cancer (UICC)) | | |
| Stage 0 | 1 (2%) | 0 (0%) |
| Stage I | 15 (34%) | 8 (28%) |
| Stage II | 13 (30%) | 11 (38%) |
| Stage III | 15 (34%) | 9 (31%) |
| Stage IV | 0 (0%) | 1 (3%) |
| Radical surgery (CRM > 1 mm) ^b | 39 (91%) ^b | 26 (93%) ^b |
| Neo-adjuvant treatment | | |
| Radiotherapy | 39 (89%) | 21 (72%) |
| Chemotherapy | 10 (23%) | 4 (14%) |
| Adjuvant treatment | 14 (32%) | 9 (31%) |
| Intraoperative bowel perforation | 5 (11%) | 3 (10%) |
| Bleeding (L) | 0.9 (0–6.0) | 0.6 (0.05–2.3) |
| Laparoscopic procedure | 7 (16%) | 7 (24%) |
| Hospital stay (days) | 10 (6–36) | 10 (7–47) |
| Local recurrence | 0 (0%) | 1 (3%) ^c |
| Follow-up time at time of questionnaire send-out | 50 (13–83) | 35 (14–84) |

^a data missing on four men and three women.

^b One patient was p-stadium 0, thus not eligible for evaluation of radical surgery. In one patient CRM was not properly evaluated.

^c Patient curatively treated for local recurrence in march 2005 – no signs of recurrent disease since then.

Table 2
Socioeconomic demographics.^a

| | Men (n = 44) | Female (n = 29) |
|---|--------------|-----------------|
| Residential area | | |
| Rural area | 3/44 (7%) | 0/29 (0%) |
| Smaller town | 7/44 (16%) | 10/29 (35%) |
| Larger city >100 000 inhabitants | 34/44 (77%) | 19/29 (66%) |
| Marital status ($p < 0.05$) | | |
| Married or living together in a relationship | 34/44 (79%) | 14/28 (50%) |
| Living alone but in a relationship | 2/44 (5%) | 0 (0%) |
| Living alone, no relationship | 7/44 (16%) | 14/28 (50%) |
| Highest level of education | | |
| Elementary school | 14/44 (32%) | 6/28 (21%) |
| Secondary school | 10/44 (23%) | 9/28 (32%) |
| Vocational education | 5/44 (11%) | 4/28 (14%) |
| College/University | 9/44 (21%) | 5/28 (18%) |
| Other | 6/44 (14%) | 4/28 (14%) |
| Occupation prior to surgery for rectal cancer | | |
| Retired | 21/44 (48%) | 18/29 (62%) |
| Employed | 20/44 (45%) | 9/29 (31%) |
| Other/student/unemployed/sick-leave | 3/44 (7%) | 2/29 (7%) |

^a Some patients did not reply to all questions, the number of patients is given in each table cell.

these were married or living together with someone in a relationship. The median age of patients sexually active within the last month was lower than those sexually inactive (54 (35–71) vs. 69 (35–89), $p < 0.0001$).

When asked if they had taken any initiative to sexual activity with their partner or other sexual contacts, 6/7 (86%) of the sexually active women responded yes, and 10/11 (91%) of the sexually active men. Two men reporting to be sexually inactive had taken initiative to sex, but had not engaged in sexual activity.

3.3. Sexual function

The questions on sexual function are presented in Table 4. There were some patients who were unable to reach orgasm prior to surgery, 1/26 women and 3/43 men, and the numbers increased after surgery, with no difference between women and men. Three men (7%) reported that they were unable to have an erection prior to surgery. Many sexually active women reported dyspareunia.

3.4. Quality of sexual health

The questions on sexual health are presented in Table 5. Men had more thoughts about sex than women and were less satisfied with their sexual health. Most men (93%) reported being bothered

Table 3
Psychological symptoms within the last month.^a

| | Male (n = 44) | Women (n = 29) |
|--|---------------|----------------|
| Physical function the last month | | |
| Low general physical capacity ($p < 0.05$) | 23/43 (54%) | 22/28 (79%) |
| Low or moderate physical health | 21/43 (49%) | 20/28 (71%) |
| Psychological function the last month | | |
| Worry or anxiety (moderate or high) | 16/43 (37%) | 6/28 (21%) |
| Life feels meaningless (moderate or high) | 12/43 (28%) | 10/28 (36%) |
| Feeling gloomy/depressed (moderate or high) | 21/43 (49%) | 10/28 (36%) |
| Low or moderate psychological well-being | 17/43 (40%) | 13/28 (46%) |
| Low or moderate subjective quality of life | 19/43 (44%) | 17/27 (63%) |
| Do you feel depressed? | | |
| No | 39/43 (91%) | 20/25 (80%) |
| Yes | 2/43 (5%) | 2/25 (8%) |
| "I don't know" | 2/43 (5%) | 3/25 (12%) |

^a Some patients did not reply to all questions; the number of patients is given in each table cell.

Table 4
Sexual function.^a

| | Men (<i>n</i> = 44) number of yes-answers | Women (<i>n</i> = 29) number of yes-answers |
|---|---|---|
| Has your ability to reach an orgasm been reduced after your surgical treatment for rectal cancer? | 19/43 (44%) | 9/26 (35%) |
| Has your erection been diminished after your surgical treatment for rectal cancer? | 32/43 (74%) | N/A |
| Has your labia been swelling during sexual arousal the last month? | N/A | 7/28 (25%) |
| Has your vagina been lubricated during sexual arousal the last month? | N/A | 10/28 (36%) |
| Have you had any ability to feel tactile sensation to your labia or clitoris the last month? | N/A | 11/26 (42%) |
| Have you had any ability to feel tactile sensation to your vagina the last month? | N/A | 10/27 (37%) |
| Have you had a poor or reduced elasticity of your vagina the last month? | N/A | 2/27 (7%) |
| Have you experienced pain around your labia or vulva during sexual activity the last month? ^b | N/A | 6/7 (86%) |
| Have you experienced pain inside your vagina or deep in your pelvis during sexual intercourse or similar the last month? ^b | N/A | 3/7 (43%) |

^a Some patients did not reply to all questions.^b Only sexually active women included.

by their sexual health the last month, which was significantly higher than among female patients (60%) ($p < 0.05$). The diminished erectile function was deemed by the men to negatively affect them and their self-esteem.

3.5. Information regarding sexual function

Most of the patients did not perceive that they had received preoperative information preparing them for a possible sexual dysfunction postoperatively (Table 6). Men were to a higher degree informed than women ($p < 0.05$). No women were referred to a specialist for sexual problems, compared to 5/43 men.

4. Discussion

This study shows that both men and women experience sexual dysfunction after rectal cancer surgery. The effect on sexual activity is difficult to assess in our study, as the patients were not interviewed pre-operatively. However, it has been reported previously that in a healthy population of Swedish men aged 70, two thirds had sexual intercourse within the last year, and the corresponding figure was 1/3 for women [32]. The time frame and median age of sexually active patients in our study makes comparisons a little difficult. However, when comparing with a European study regarding sexual function among men [33], the male patients in our cohort seem to report lower sexual activity than an average healthy population.

Regarding sexual dysfunction, erectile dysfunction (ED) is a common problem in men affecting about 30% of all men in an average European population, and it increases with age [33]. In our study only 7% reported ED prior to surgery, which may indicate that some men were not reporting their preoperative dysfunction. However, our data with 74% ED after surgery corresponds with previous reports in the literature [3,6,8,9,34].

Female sexual dysfunction is less reported in the literature, but our results after rectal cancer surgery confirm previous studies with dyspareunia and reduced ability to achieve orgasm [3].

A low sexual satisfaction among men after rectal cancer surgery has been reported previously [3,35–37], but there is little reported regarding female sexual satisfaction. In our study we found that women were more satisfied with their sexual health than men regardless of sexual activity within the last month.

There is data pointing to a relationship between psychological well being and sexual function as well as quality of sexual health [13–15]. We analysed different aspects of physical and psychological functions, and found that very few of our subjects were depressed or had a high level of anxiety. Previous studies have

shown that depression has less effect on sexual health in an elderly population compared to younger populations [38]. Thus, it may be assumed that the influence by depression on the results of this study is small.

A few previous studies have indicated an increased need for preoperative information regarding sexual function [3,22]. Our study confirms this and also stresses the importance of giving information to female patients. We do not have proper documentation as to what extent the patients actually were informed and their answers probably mirror their remembrance of the preoperative information. Still, the fact that a majority reported a lack of information is sufficient to state that, if informed, the patients could not retain the information. Thus there is room for improvement.

There are limitations to this study, which must be taken into consideration when interpreting data. The follow-up time is at least one year, but varies as the questionnaires were sent out on one occasion, whereas the patients had been operated during a six year time frame. However, there is data from other sources indicating that sexual function remains stable over time [11,39]. Also, although it would have been interesting to have preoperative data on sexual function as reference data, answers could possibly be misleading as they would be coloured by the life changing event of being in the midst of receiving a cancer diagnosis. Previous studies have shown that focusing on cancer cure is superior to thoughts of sexual function for patients [3,40], and this is probably even truer at the time of diagnosis.

Another limitation is the size of the patient cohort. However, our material is consecutive with patients from the same hospital during a limited time period, which could make up for the small size of the cohort. This study must be considered exploratory and it shows that there are issues that need to be addressed in larger confirmatory studies. Another limitation is that preoperative information was not documented in conjunction with this study. The patients were asked about information given more than three years ago. It is possible that questions should have been asked at another time point or in another manner to fully explore the preoperative information. However, the fact still remains that the patients did not remember receiving any information, which indicates that additional, perhaps also written, information could be beneficial.

In conclusion, sexual dysfunction following APE was considerable for both men and women, but men were more bothered by their sexual dysfunction than women. Patients did not seem to have been sufficiently informed preoperatively and this needs to be improved. An increased focus on preoperative information as well as on the treatment of sexual dysfunction would probably be beneficial for rectal cancer patients.

Table 5
Quality of sexual health.^a

| | Men (n = 44) number of yes-answers | Women (n = 29) number of yes-answers |
|---|------------------------------------|--------------------------------------|
| Have you had thoughts or desire for sex the last month? ($p < 0.05$) | 34/44 (77%) | 14/29 (48%) |
| Has sex been important to you (regardless of whether you have a partner or not) the last month? | 21/44 (48%) | 9/29 (31%) |
| Have you refrained from sexual activity out of fear of failure the last month? | 9/44 (21%) | 5/29 (17%) |
| Have you felt sexually attractive the last month? | 13/44 (30%) | 9/29 (31%) |
| Are you satisfied with your sexuality and your current sexual life, as it has been the last month (regardless of whether you have a partner or not)? ($p < 0.05$) | 17/42 (41%) | 16/23 (70%) |
| Have you had any bother/dissatisfaction regarding your sexual life the last month? ($p < 0.05$) | 39/42 (93%) | 16/27 (60%) |
| If your bother/dissatisfaction regarding your sexual life would remain the same for the rest of your life as it has been the last month, would that affect you negatively? | 31/39 (80%) | 12/16 (75%) |
| Have you ever worried that something embarrassing will happen during sexual activity due to your stoma - this question is not limited to the last month, any sexual activity after the rectal cancer treatment applies. | 11/22 (50%) | 4/10 (40%) |
| If you have a reduced or diminished erection after your rectal cancer surgery, has that negatively affected your self-esteem? ^b | 26/32 (80%) | N/A |
| If you have a reduced or diminished erection after your rectal cancer surgery, and that would remain the same for the rest of your life, would that affect you negatively? ^b | 28/32 (88%) | N/A |

^a Some patients did not reply to all questions; the number of patients is given in each table cell.

^b Only including patients that reported a reduced or diminished function ($n = 32$).

Table 6
Information regarding sexual function after rectal cancer treatment.

| | Men (n = 44) Number of yes-answers | Women (n = 29) number of yes-answers |
|---|---------------------------------------|--------------------------------------|
| Were you at least somewhat prepared preoperatively for the sexual bother/dissatisfaction you have today? ($p < 0.05$) | 19/43 (44%) | 4/28 (14%) |
| Have you been referred to a specialist (gynaecologist or urologist) because of your sexual bother/dissatisfaction? | 5/43 (12%) | 0/27 (0%) |

Ethical approval

The local ethics committee in Gothenburg approved the study (#407-10).

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Author contribution

Drs Angenete, Haglind, Andersson and Asplund had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Angenete and Haglind. Acquisition of data: Angenete, Haglind and Asplund. Analysis and interpretation of data: Angenete, Haglind, Andersson and Asplund. Drafting of the manuscript: Angenete. Critical revision of the manuscript for important intellectual content: Angenete, Asplund, Andersson, and Haglind. Final approval of the manuscript: Angenete, Asplund, Andersson and Haglind. Statistical analysis: Angenete. Obtained funding: Angenete and Haglind. Administrative, technical, and material support: Angenete and Haglind. Study supervision: Angenete.

Conflict of interest statement

None.

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