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## Distressful Symptoms after Radical Cystectomy with Urinary Diversion for Urinary Bladder Cancer: A Swedish Population-Based Study

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### Key Words

Cystectomy · Urinary diversion · Bladder neoplasm · Quality of life

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### Abstract

**Objective:** To study the excess prevalence of distressful symptoms after radical surgery for urinary bladder cancer.

**Methods:** We included all patients who underwent cystectomy due to bladder cancer before 1996 in Stockholm County. A control group was randomly selected from the general population. Information was collected by means of an anonymous postal questionnaire.

**Results:** Completed questionnaires were returned by 310 (71%) controls and 251 (85%) cystectomized individuals. A 5-fold (reservoir) and 9-fold (conduit) increase in defecation urgency and a 4-fold (reservoir) and 6-fold (conduit) increase in faecal leakage were reported in individuals operated on. Urinary tract infection was increased 3-fold in cystectomized individuals compared with controls, during the previous year 26% of the patients reported a symptomatic infection. The perception of a reduced physical attractiveness due to disease was more than 5-fold increased in the men operated on compared to the controls. The majority, 135 out of 201 (67%), reported that they would have refused alternative bladder-sparing procedures if they decreased the prospects of survival by even as little as 1%.

**Conclusions:** The patient's situation after cystectomy is considerably impaired due to changed bowel and sexual function, urinary tract infections and a sense of decreased attractiveness. However, most patients are in spite of this unwilling to compromise survival.

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## Introduction

No one doubts that removal of a muscle-involving urinary bladder malignancy – a radical cystectomy – cures many patients of a life-threatening disease. However, surgery also implies altered urinary, bowel and sexual function [1, 2]. The magnitude of the excess symptom occurrence after cystectomy is not known – no comparison with untreated patients has been made. Furthermore, no one has documented the amount of distress from specific symptoms or the extent to which patients are willing to trade off survival for a reduced symptom burden.

In 1950, Eugene Bricker [3] described a major innovation in urinary diversion constructing an ileal conduit and about two decades later, Nils G. Kock [4] and Donald G. Skinner [5] popularized the concept of continent cutaneous urinary diversion. Another decade later, reconstruction of the lower urinary tract with orthotopic intestinal neobladders connected to the urethra had become established clinical practice [6]. An alternative strategy is to give radiotherapy (and/or cytostatics) initially and reserve cystectomy for patients without complete tumour remission [7–11].

Little effort has been made to study the distress of disturbed bowel and sexual function. A detailed study of the excess symptom occurrence (and the corresponding distress) after the operation may provide clues as to how the situation of today's patients can be improved. Knowledge of the patients' priorities with regard to optimal survival possibilities and avoiding symptoms may guide the choice of means for bettering the postoperative situation. Here we report data on patients treated with cystectomy and urostomy (conduit or reservoir) and population controls.

## Patients and Methods

All patients with locally aggressive bladder cancer who underwent cystectomy in Stockholm County between January 1969 and December 1995 were identified. Between September 1996 and April 1998, patients between the ages of 40 and 85 who were alive in September 1996 ( $n = 294$ ) were sent a letter explaining the objectives of the study and an invitation to participate. A control group of 434 men and women without urinary bladder cancer, randomly selected from the Swedish Population Register and frequency matched by sex, age and region of residence, also received an invitation. Those who did not return the enclosed response form within 2 weeks were telephoned. Thirty-one of the cystectomized men and women and 26 from the originally retrieved control group were excluded because of erroneous register data (table 1). The study was approved by the Regional Ethics Committee of the Karolinska Institute.

A total of 251 (85%) cystectomized individuals and 310 (71%) controls agreed to take part in the study. A questionnaire was sent by mail to be answered anonymously along with a registration form to be

returned separately. Treatment-related information was obtained from the patients in order to safeguard anonymity. After excluding 15 patients with recurrence, and 12 patients with orthotopic neobladders, 224 cystectomized men and women remained: 169 with a conduit and 55 with a reservoir. Reasons for not participating, exclusion criteria and population characteristics are listed in table 1.

The questionnaire, which had been developed on the basis of successive in-depth interviews with patients and clinicians, was similar to our questionnaire on male [12] and female [13] sexual function and contained 137 questions for the cystectomy subjects and 125 questions for the controls. It was designed to evaluate symptoms of urinary dysfunction (e.g., urinary tract infections, leakage and odour), bowel dysfunction (e.g., abdominal pain, diarrhoea and faecal leakage) and sexual dysfunction (e.g., reduced sexual interest and orgasmic pleasure, vaginal changes in women and erectile dysfunction in men). The prevalence of erectile dysfunction was assessed using the method described by Helgason et al. [14].

Some characteristics of each symptom (quality, occurrence, intensity or duration) and, separately, the amount of distress it caused were assessed. The occurrence of symptoms was measured in the individual either with a 'verbal' incidence or prevalence scale. Symptom intensity was typically assessed on a 'verbal' 4-category scale (none/little/moderate/much) [15] and symptom duration by the specified time. The corresponding distress was measured on a 'verbal' 4-category scale. To exemplify the question 'Have you experienced, during the past 6 months, difficulties in suppressing the urge to defecate before reaching the toilet (defecation urgency)?' could be answered in the following six ways: 'Never/almost never', 'Less than on one of five occasions', 'Less than on half of all occasions', 'On about half of all occasions', 'More than on half of all occasions', and 'Always/almost always'. The corresponding distress was assessed on a 'verbal' scale of intensity by the question 'If you have experienced disordered bowel function during the past 6 months and this were to persist for the rest of your life, how would you feel about it?' The possible answers were 'Not relevant', 'It does not distress me at all', 'It distresses me a little', 'It distresses me moderately', and 'It distresses me a lot'. To determine whether a treatment influenced symptom distress, we examined the proportion of individuals with moderate or much symptom distress, excluding those not having the symptom. Some psychological symptoms and global measures were reported on a 7-category visual digital scale covering, for example, Lowest possible well-being and Best possible well-being.

In a trade-off question, the cystectomized subjects and controls were asked to consider hypothetically the option of risking a poorer prognosis if it had been possible for them to choose to exclude radical organ-removing surgery and choose instead an alternative bladder-sparing procedure. The symptoms were said to occur or not occur while the risk of a shortened survival was directly specified on a vertical line (0, 1, 5, 10, 20, 30...90 and 100%).

Questions concerning potential confounding and effect-modifying variables were identical to those we have used previously [12, 16]. We assessed, for example, level of education, occupation, employment status, smoking habits, and concurrent diseases and their treatment.

### *Surgical Technique and Preoperative Irradiation*

The surgery performed is a modification of that described by Skinner [17]. It includes a bilateral lymphadenectomy in addition to excision of the urinary bladder, prostate and perivesical fat. Urethra was routinely removed during this period. In women, an anterior pelvic exenteration with a wide excision of the bladder in continuity with

**Table 1.** Characteristics of the men and women treated with cystectomy due to urinary bladder cancer and the controls<sup>a</sup>

Characteristic	Controls		Patients treated with cystectomy	
Total identified in registers	460		325	
Dead at follow up, n (%)	16	(3)	13	(4)
Erroneous age/diagnosis	–		13	(4)
Language problems	2	(0.4)	0	
Emigrated	4	(0.9)	4	(1)
Other, nonexistence in recent registers	4	(0.9)	1	(0.3)
Number of invitations to participate	434 (100)		294 (100)	
Reasons for nonparticipation				
Intercurrent disorder	27	(6)	14	(5)
Contact not established	2	(0.5)	5	(2)
Lost questionnaire	0		1	(0.3)
Refusal	70	(16)	16	(5)
Unknown	17	(4)	2	(0.7)
Diseased during follow-up	1	(0.2)	0	
Questionnaire discrepancy	7	(2)	6	(2)
Total completing the questionnaire, n (%)	310 (71)		251 (85)	
Exclusion criteria				
Recurrence at follow-up	–		15	
Orthotopic bladder substitution	–		12	

Characteristic	Controls		Patients with continent urostomy		Patients with noncontinent urostomy	
Total number in each group	310		55		169	
Age, mean						
At follow-up, years	Women	73.3±0.9	63.6±2.3	75.3±1.3		
	Men	73.0±0.6	66.3±1.3	71.6±0.7		
At operation, years	Women	–	57.1±2.2	64.7±1.6		
	Men	–	60.1±1.4	61.2±0.8		
Gender – proportion (%)						
Women	99/308	(32)	17/55	(31)	41/168	(24)
Men	209/308	(68)	38/55	(69)	127/168	(76)
Material status – proportion (%)						
Married or living with a partner	204/306	(67)	37/52	(71)	106/164	(65)
Has a partner but lives alone	18/306	(6)	3/52	(6)	14/164	(9)
Single	23/306	(8)	8/52	(15)	20/164	(12)
Widow/widower	61/306	(20)	4/52	(8)	24/164	(15)
Employment status – proportion (%)						
Working	35/304	(12)	13/47	(28)	12/152	(8)
On sick leave	6/304	(2)	4/47	(9)	9/152	(6)
Unemployed	3/304	(1)	2/47	(4)	1/152	(1)
Retired	259/304	(85)	27/47	(57)	130/152	(86)
Level of education – proportion (%)						
Primary school	145/302	(48)	20/53	(38)	78/158	(49)
Secondary school	92/302	(31)	20/53	(38)	52/158	(33)
University	65/302	(22)	13/53	(25)	26/158	(17)
Unknown					2/158	(1)
Born in Sweden – proportion (%)	283/305	(93)	43/53	(81)	148/162	(91)
Preoperative irradiation	–		22/54	(41)	111/165	(67)
Preoperative chemotherapy	–		20/53	(38)	59/160	(37)
Reoperation with changed urinary diversion	–		6/55	(11)	3/165	(2)
Daily smoker, 1 year or more – proportion (%)						
Never smoked	143/310	(46)	9/55	(16)	41/169	(24)
Former smoker	111/310	(36)	25/55	(45)	62/169	(36)
Current smoker	48/310	(15)	19/55	(35)	49/169	(29)
Time to complete questionnaire, h	1.2		1.4		1.5	

<sup>a</sup> Plus-minus values are means ± SEM. Percentages may not add up to 100 because of rounding.

the uterus, fallopian tubes, ovaries, and the anterior wall of the vagina is usually recommended but, in this series, the vagina and internal genitals were left intact. The majority of the patients receiving a conduit were operated with the Bricker technique, using approximately 10 cm of the small intestine 30 cm from the ileocecal valve [3]. A few patients from one hospital received a colon conduit utilizing 15–20 cm of the sigmoid colon [18]. The surgical technique described by Kock et al. [4] was used for all continent urinary reservoirs. About 60–70 cm of the small intestine 50 cm proximal to the ileocecal valve is needed for the construction of an ileal reservoir with this technique.

Preoperative irradiation was given to almost all patients in the years 1969–1988 (40 Gy in 4 weeks 1969–1978, and 20 Gy in 5 days 1979–1988). The field was restricted to the urinary bladder; no effort was made to include lymph nodes in the target. Totally, 67% of the patients with a conduit and 41% of the patients with a reservoir received preoperative irradiation.

#### *Statistical Analysis*

On the population level, we calculated the percentage of subjects with a certain incidence, prevalence, intensity, duration, or distress of a symptom. To compare groups, we estimated relative risks: the percentage of, for example, subjects operated on reporting the outcome divided by the percentage of controls reporting the same outcome. Sex- and age-adjusted relative risks, as well as the associated 95% confidence intervals, were calculated by the Mantel-Haenszel method [19, 20].

## **Results**

#### *Bowel Function* (table 2)

Urgency in connection with at least half of the perceived defecational impulses was increased 5-fold in patients with a reservoir and 9-fold in patients with a conduit compared to controls. Furthermore, a 4-fold (reservoir) and 6-fold (conduit) increase in faecal leakage and a 2-fold increase in abdominal pain were observed.

Altogether, bowel symptoms were reported by 85 (28%) of the 304 control men and women, 31 (58%) of the 53 patients with a reservoir, and 83 (52%) of the 160 patients with a conduit (not in table). There was a 3-fold increase in bowel symptom distress among cystectomized patients compared to the controls. 20% of the preoperatively irradiated patients were moderately or very much distressed by bowel symptoms compared to 22% of the nonirradiated patients (not in table). The assessed bowel symptoms were altered only to a small degree (if at all) by radiotherapy, and adjusting for preoperative irradiation did not alter the results (data not shown).

#### *Urinary Function* (table 3)

Surgery caused a 6-fold (conduit) and 7-fold (reservoir) increase in the incidence of urinary tract infections with fever. A 7-fold (conduit) and 4-fold (reservoir) increase in

the prevalence of urine odour were reported. Thirteen (8%) out of 167 patients with conduit reported urinary leakage (all magnitudes) at least once a month compared to 10 (18%) out of 55 with reservoir.

Overall, 94 (32%) of the 298 controls reported urinary symptoms. The corresponding figures were for persons with a conduit 85 (55%) out of 155 and for those with a reservoir 32 (60%) out of 52 (not in table). There was a 2-fold increase in urinary symptom distress in the cystectomized men and women. Adjusting for preoperative irradiation did not alter the results (data not shown).

#### *Sexual Function in Women* (table 4)

Low sexual satisfaction was reported by 15 (25%) out of 59 female controls compared to 5 (45%) out of 11 women with a reservoir and 4 (21%) out of 19 women with a conduit. Sexual interest was generally lower in women than in men and few women in this series were sexually active during the study period. The perceived reduction in physical attractiveness due to disease (patients and controls) or the urostomy (patients) was increased more than 10-fold among the cystectomized women compared to the control women. Distress due to low physical attractiveness was increased 4-fold in the women operated on compared to the controls (table 3).

Urogenital mucosal problems were reported by 3 (18%) out of 16 women with a reservoir and by 3 (10%) out of 29 with a conduit and 1 (1%) out of 73 female controls. Preoperative irradiation did not alter these results (data not shown).

#### *Sexual Function in Men* (table 5)

Low satisfaction with their present sexuality/sexual life was twice as high in cystectomized men as in male controls. All men operated on lost the ability to ejaculate and the relative risk for erectile dysfunction was twice as high as in controls. A larger percentage of men with a conduit felt no or only low interest in sexuality/sexual life compared to controls, RR = 1.3. The perceived reduction in physical attractiveness due to disease (patients and controls) or the urostomy (patients) was increased 5-fold (conduit) and 6-fold (reservoir) in the men operated on compared to controls (table 3).

#### *Lymphoedema* (not in table)

Surgery did not cause an increase in the prevalence of lymphoedema. 'Swollen legs or lower abdomen' at least every month was reported by 35 (12%) out of 303 controls, and respective figures for patients with conduit and reservoir were 22 out of 161 (14%) and 4 out of 55 (7%). Com-

**Table 2.** Bowel symptoms during previous 6 months, occurrence and distress, age and sex-adjusted relative risks

Variable	Controls (n = 310)	Patients with reservoir (n = 55)	Patients with conduit (n = 168)
Abdominal pain at least once per month, n/total n (%)	23/306 (8)	7/54 (13)	21/163 (13)
Relative risk for patients vs. controls	1.0	2.6 (1.0–6.7)	1.9 (1.1–3.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.4 (0.6–3.7)
Frequent defecation more than 14 times/week, n/total n (%)	10/300 (3)	4/55 (7)	21/160 (13)
Relative risk for patients vs. controls	1.0	1.9 (0.6–5.5)	3.6 (1.9–6.8)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.6 (0.6–4.0)
Diarrhoea/loose stools at least once a month, n/total n (%)	35/309 (11)	11/54 (20)	54/162 (33)
Relative risk for patients vs. controls	1.0	1.7 (0.9–3.4)	3.0 (2.1–4.3)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	2.0 (1.1–3.7)
Constipation at least once a month, n/total n (%)	35/307 (11)	11/54 (20)	15/163 (9)
Relative risk for patients vs. controls	1.0	2.0 (1.0–4.0)	0.9 (0.5–1.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.4 (0.2–1.0)
Defecation urgency every other time or more, n/total n (%)	6/305 (2)	3/53 (6)	29/161 (18)
Relative risk for patients vs. controls	1.0	5.2 (1.2–23.2)	9.5 (4.8–18.8)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	4.5 (1.3–15.3)
Faecal leakage at least once a month, n/total n (%)	5/304 (2)	4/53 (8)	15/163 (9)
Relative risk for patients vs. controls	1.0	4.2 (1.3–14.1)	6.2 (2.4–16.0)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.4 (0.4–5.4)
Blood or phlegm in stool at least once a month, n/total n (%)	5/306 (2)	1/54 (2)	7/163 (4)
Relative risk for patients vs. controls	1.0	0.7 (0.1–6.2)	2.5 (0.8–7.5)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	3.3 (0.5–21.9)
<i>Symptom distress in whole group</i>			
Moderate or substantial distress if current problems from gastrointestinal tract persist, n/total n (%)	25/304 (8)	11/53 (21)	38/160 (24)
Relative risk for patients vs. controls	1.0	3.8 (1.8–7.9)	3.1 (2.4–4.9)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.7 (0.8–3.5)

<sup>a</sup> Restricted to patients with maximum age of 76.

pared to controls, the age-adjusted relative risks with 95% confidence intervals were 1.3 (0.8–2.1) for those with a conduit and 0.8 (0.3–2.1) for those with a reservoir. The relative risk of experiencing heaviness in the legs or lower abdomen at least monthly was 1.6 (1.0–2.6) and 1.2 (0.5–3.1), respectively. Preoperative irradiation did not significantly alter the results (not in table).

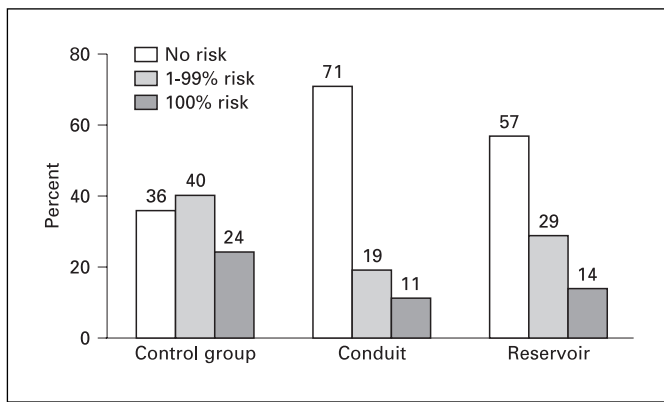
#### *Well-Being (table 6) and Social Life*

The prevalence of poor psychological and physical well-being, fatigue (low energy level) and high-level depression was somewhat increased in the cystectomized subjects. Surgery did not affect travel frequency: 202 (97%) out of 209 controls, 113 (94%) out of 120 patients with a conduit and 48 (98%) out of 49 patients with a reservoir had taken one or more trips away from their hometown the previous year. However, 8 patients (5%) with a conduit versus none with a reservoir felt hindered by the urinary diversion (moderately or much) from shopping and 12 (7%) versus 1 (2%),

respectively, felt hindered from accepting invitations to social functions (not in table).

#### *Trade-Off (fig. 1)*

68% (135/201) of the cystectomized individuals were unwilling to take any risk of shorter survival as a trade-off for alternative bladder sparing procedures with a reduced symptom burden. The cystectomized men were more willing to trade off (53/150; 35%) than the women (13/50; 26%), and patients with a conduit were less willing to trade off (44/150; 29%) than those with a reservoir (22/50; 44%). Twenty-three of the 200 patients (12%) would retain their urinary bladder even if the risk for reduced survival was 100%. Age, social and marital status, country of birth, anxiety and depression did not significantly influenced the trade-off judgement. There was a tendency for higher risk-taking in patients not belonging to the Swedish state church (RR = 2.2, confidence interval = 1.3–3.6) (not in table).



**Fig. 1.** Trade off: the proportion of subjects in each group willing to avoid radical organ-removing surgery to different risks of shortened survival.

## Discussion

Cystectomy with urinary diversion causes an excess prevalence of symptom distress arising from dysfunctional defecation (diarrhoea, defecation urgency and faecal leakage), compromised sexual function, and problems related to the urinary diversion (urinary tract infections, odour). However, despite the symptom distress among the cystectomized patients (and a lower average rating of psychological and physical well-being), 67% were unwilling to trade off survival to diminish the symptom burden. Only 11% of the patients said they would have chosen treatment options with less symptom distress if they had known that survival would be shortened.

In the light of the substantial influence of radical cystectomy on bowel function demonstrated in our study, it is surprising that defecation has been assessed in only one previously published series of patients [2]. We found an excess prevalence of nearly every gastrointestinal symptom covered, and one quarter of the persons operated on reported moderate or much symptom distress from disordered bowel function in the summarizing question. Defecation urgency is probably caused by nerve dysfunction, either by direct surgical damage to nerves, altered metabolism (e.g., due to malabsorption of electrolytes and vitamins) [21], or occurs secondarily to surrounding tissue fibrosis. Deficient physiological function of the pelvic floor muscles (or of sphincter muscles) caused by direct injury to the muscles or nerves results in faecal leakage. In our study, bowel function was not altered by the preoperative external radiation. Possible reasons include the low total dose and the limited relative dose given to the bowel. In a report by N'Dow et al. [2] they found a similar risk for bowel symptoms as in our study, 54

vs. 58% respectively, but only in patients operated with clam enterocystoplasty for detrusor instability. Our restriction to cancer patients could explain the differences.

We found that the surgical alterations of the urinary tract results in an excess occurrence of symptomatic urinary tract infections. The diagnostic search for bacteria in the urine is probably more intense in cystectomized patients than in controls, which would introduce an error in the comparison. Presumably, this source of error does explain only to a small extent, if at all, the observed differences in symptomatic infections. About 75% of patients with a conduit have infected urine [22]. When it occurred, the urinary tract infection was not reported to cause more distress among the subjects operated on than among controls.

The odour of urine is an issue after cystectomy. Approximately one tenth of the surgery patients reported the smell of urine (at least every month), and it was classified as distressing (moderate or very much) by about 40% (not in table).

Since the prostate is routinely extirpated in a radical cystectomy, it is no surprise that men lost their ability to ejaculate and that all but 12 (92%) of them reported erectile dysfunction. In addition, all men operated before 1989 had a ureterectomy as a standard procedure and nerve-sparing surgery was never attempted during the study period. We found both here and in previous studies on men with prostate cancer [12] that approximately half of them in the studied age group (50–80 years) are distressed by their erectile dysfunction.

In the present series, the vagina was left intact during surgery, which may explain why only 3 (6%) of the 48 women operated on reported moderate or much distress from vaginal changes (reduced elasticity and length), which is similar to the figures among controls (4/80, 5%) and clearly below what we found in women treated for cervical cancer, 62 out of 243 (26%) [13]. However, the small numbers limit the value of our data concerning sexual function in these women. Our data do not support the hypothesis that a radical cystectomy influences vaginal lubrication during intercourse, in contrast to our finding in a previous study that radical hysterectomy increases the prevalence of this symptom 3-fold [13].

One fifth (10/49) of the women operated on had had intercourse during the previous 6 months, a figure slightly below that among the controls (22/82; 27%). Few women reported that their urinary diversion affected their sexual life. The majority, 75% of the controls and 76% of the cystectomized women, had no or minimal interest in sex. This low-level interest results in reduced sexual activity.

We detected no alteration in the prevalence of lymphoedema after cystectomy. We have previously found that

**Table 3.** Urinary symptoms during previous 12 months, occurrence and distress, age and sex-adjusted relative risks

Variable	Controls (n = 310)	Patients with reservoir (n = 55)	Patients with conduit (n = 168)
One or more urinary tract infections (UTIs), n/total n (%)	28/299 (9)	14/52 (27)	41/157 (26)
Relative risk for patients vs. controls	1.0	3.7 (1.9–7.5)	3.0 (2.0–4.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.9 (0.4–1.7)
UTI with fever, one or more, n/total n (%)	9/256 (4)	12/52 (23)	27/150 (18)
Relative risk for patients vs. controls	1.0	7.1 (2.9–17.6)	5.9 (3.0–11.5)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.7 (0.3–1.5)
UTI with pain, one or more, n/total n (%)	15/251 (6)	4/52 (8)	19/147 (13)
Relative risk for patients vs. controls	1.0	1.3 (0.4–4.2)	2.4 (1.3–4.7)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.5 (0.4–4.9)
UTI with other symptoms, one or more, n/total n (%)	11/252 (4)	8/51 (16)	21/147 (14)
Relative risk for patients vs. controls	1.0	4.4 (1.6–12.6)	3.5 (1.9–6.7)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.8 (0.3–2.0)
Urinary leakage at least once a month, n/total n (%)	31/308 (10)	10/55 (18)	13/167 (8)
Relative risk for patients vs. controls	1.0	2.0 (0.9–4.5)	0.8 (0.4–1.5)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.3 (0.1–0.8)
Urinary leakage, moderate or large, n/total n (%) <sup>b</sup>	18/93 (19)	6/31 (19)	25/72 (34)
Relative risk for patients vs. controls	1.0	1.3 (0.4–3.8)	2.3 (1.3–3.9)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	2.2 (0.9–5.2)
Odour of urine at least once a month, n/total n (%)	6/308 (2)	4/52 (8)	19/161 (12)
Relative risk for patients vs. controls	1.0	4.3 (1.0–18.5)	6.7 (3.1–14.8)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.7 (0.6–5.0)
<i>Symptom distress in whole group</i>			
Moderate or substantial distress if current problems involving urinary tract persist, n/total n (%)	36/298 (12)	12/53 (23)	29/155 (19)
Relative risk for patients vs. controls	1.0	2.0 (1.0–3.9)	1.5 (1.0–2.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.0 (0.5–2.0)
<i>Men</i>			
Moderate or substantial feeling of decreased attractiveness as a consequence of disease or the operation, n/total n (%)	1/77 (1)	2/16 (13)	6/32 (19)
Relative risk for patients vs. controls	1.0	11.2 (0.6–218)	13.0 (2.8–59.5)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	2.6 (0.5–14.9)
Moderate or substantial distress if feeling of decreased attractiveness persist, n/total n (%)	4/77 (5)	3/16 (19)	7/32 (22)
Relative risk for patients vs. controls	1.0	3.6 (0.9–14.6)	3.9 (1.3–11.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	2.4 (0.6–9.4)
<i>Women</i>			
Moderate or substantial feeling of decreased attractiveness as a consequence of disease or the operation, n/total n (%)	12/195 (6)	18/35 (51)	32/110 (29)
Relative risk for patients vs. controls	1.0	6.4 (3.5–12.0)	4.5 (2.6–7.7)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.6 (0.4–1.0)
Moderate or substantial distress if feeling of decreased attractiveness persist, n/total n (%)	17/194 (9)	3/35 (51)	28/111 (25)
Relative risk for patients vs. controls	1.0	5.4 (3.0–10.0)	2.9 (1.7–4.9)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.5 (0.3–0.8)

<sup>a</sup> The analysis was restricted to patients with a maximum age of 76.

<sup>b</sup> The analysis was restricted to patients with the symptom.

**Table 4.** Sexually related symptoms among women during previous 6 months, occurrence and symptom distress age-adjusted relative risks

Variable	Controls (n = 100)		Patients with reservoir (n = 17)		Patients with conduit (n = 39)	
<i>Sexual activity/sexuality</i>						
Sexual desire less than once a month, n/total n (%)	66/80	(83)	11/15	(73)	30/34	(88)
Relative risk for patients vs. controls	1.0		1.1	(0.9–1.7)	1.2	(0.9–1.3)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.0	(0.6–1.4)
No intercourse, n/total n (%)	60/82	(73)	10/16	(63)	29/33	(88)
Relative risk for patients vs. controls	1.0		1.4	(0.9–2.2)	1.2	(1.0–1.4)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.1	(0.7–1.7)
No orgasm, n/total n (%)	55/81	(68)	9/15	(60)	28/32	(88)
Relative risk for patients vs. controls	1.0		1.6	(1.0–2.6)	1.2	(1.0–1.5)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.1	(0.7–1.8)
Little or no orgasmic pleasure, n/total n (%) <sup>b</sup>	5/24	(20)	1/6	(17)	0/4	(0)
Relative risk for patients vs. controls	1.0		0.6	(0.1–4.2)	–	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
<i>Vaginal changes</i>						
Insufficient vaginal lubrication at least every other time, n/total n (%) <sup>b</sup>	10/28	(36)	2/8	(25)	3/7	(43)
Relative risk for patients vs. controls	1.0		1.0	(0.2–4.0)	1.1	(0.4–3.0)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.6	(0.3–8.0)
Vaginal lubrication moderately or substantially insufficient, n/total n (%) <sup>2</sup>	7/23	(30)	0/6	(0)	2/5	(40)
Relative risk for patients vs. controls	1.0		–		1.3	(0.3–5.0)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
Moderate or substantial reduction in perceived length of vagina during intercourse, n/total n (%) <sup>b</sup>	3/22	(14)	1/5	(20)	1/5	(20)
Relative risk for patients vs. controls	1.0		1.6	(0.2–15.3)	2.0	(0.2–18.5)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.3	(0.1–16.6)
Moderate or substantial reduction in perceived elasticity of vagina during intercourse, n/total n (%) <sup>b</sup>	2/25	(8)	0/5	(0)	3/6	(50)
Relative risk for patients vs. controls	1.0		–		5.4	(1.3–21.7)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
<i>Problems during intercourse</i>						
Moderate or substantial superficial dyspareunia in previous 6 month, n/total n (%) <sup>b</sup>	2/24	(8)	0/6	(0)	2/6	(33)
Relative risk for patients vs. controls	1.0		–		3.5	(0.7–18.0)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
Moderate or substantial deep dyspareunia in previous 6 month, n/total n (%) <sup>b</sup>	1/23	(4)	0/6	(0)	1/5	(20)
Relative risk for patients vs. controls	1.0		–		4.6	(0.3–61.8)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
<i>Other</i>						
Moderate or substantial mucosal problems other than in sexual situations, n/total n (%)	1/76	(1)	3/16	(18)	3/29	(10)
Relative risk for patients vs. controls	1.0		14.3	(1.6–128)	7.9	(0.9–72.6)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.6	(0.1–2.4)
Moderate or substantial distress if mucosal problems persists, n/total n (%) <sup>c</sup>	3/17	(18)	1/6	(17)	5/6	(83)
Relative risk for patients vs. controls	1.0		0.9	(0.1–7.4)	5.9	(1.8–19.4)
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		4.8	(0.8–30.3)

<sup>a</sup> The analysis was restricted to patients with maximum age of 76.

<sup>b</sup> The analysis was restricted to sexually active women.

<sup>c</sup> The analysis was restricted to women with the symptom.

**Table 4.** (continued)

Variable	Controls (n = 100)		Patients with reservoir (n = 17)		Patients with conduit (n = 39)	
<i>Symptom distress in whole group</i>						
Little or no satisfaction with present sexuality/sexual life, n/total n (%)	15/59	(25)	5/11	(45)	4/19	(21)
Relative risk for patients vs. controls	1.0		2.4 (1.0–6.2)		0.8 (0.3–2.1)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.4 (0.1–1.5)	
No or low interest in sex, n/total n (%)	61/81	(75)	9/16	(56)	29/34	(85)
Relative risk for patients vs. controls	1.0		1.1 (0.7–1.7)		1.1 (0.9–1.3)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.0 (0.6–1.7)	
Moderate or substantial effect on sex life of urinary/urostomy symptoms, n/total n (%)	1/95	(1)	3/16	(19)	1/40	(3)
Relative risk for patients vs. controls	1.0		21.7 (1.4–329)		2.3 (0.2–33.0)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.2 (0.01–4.7)	
Moderate or substantial effect on sex life of bowel problems, n/total n (%)	0/95	(0)	1/16	(6)	0/38	(0)
Relative risk for patients vs. controls	1.0		–		–	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	
Moderate or substantial distress if experienced sexual limitations persists, n/total n (%)	8/81	(10)	2/16	(13)	1/32	(3)
Relative risk for patients vs. controls	1.0		1.3 (0.3–5.4)		0.3 (0.1–2.2)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.9 (0.1–8.2)	
Moderate or substantial distress if current vaginal changes during sexual activity persists, n/total n (%)	1/81	(1)	0/16	(0)	3/32	(9)
Relative risk for patients vs. controls	1.0		–		7.2 (1.2–42.2)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		–	

<sup>a</sup> The analysis was restricted to patients with maximum age of 76.

<sup>b</sup> The analysis was restricted to sexually active women.

<sup>c</sup> The analysis was restricted to women with the symptom.

the occurrence increases 8-fold after a radical hysterectomy with pelvic lymphadenectomy [unpubl. data]. It is likely that variations in the surgical techniques could explain the difference [23].

Lately, eradication of the tumour with cystostatics (with or without radiotherapy) has once again become an alternative to radical cystectomy [24]. Caffo et al. [25] have found a better quality of life in patients treated with conservative therapy (radiotherapy with or without chemotherapy) than with urostomy. Sixty-six (33%) of the 201 persons operated on in our study who say they would accept a certain decrease in survival to avoid the postoperative symptom burden could have been offered an alternative to radical cystectomy. Controls preferred a diminished symptom burden (to maximal survival) more often than the cystectomy subjects, which is in line with a study by Slevin et al. [26]. It is possible that they would take another position when actually faced with a life-threatening disease. We have no data from the relevant period of time, i.e., on patients with a newly diagnosed tumour.

There is no valid comparison between an organ-preserving strategy, usually restricted to T2 or T3a disease, and primary radical cystectomy with regard to survival. Multimodality bladder-sparing treatment has, however, in similar stages been reported to have a comparable 5-year survival to radical cystectomy, although survival with an intact bladder is somewhat less [11]. Thus, one may take the position that, since we do not know that organ preservation is clearly inferior in terms of survival, it might be reasonable to offer all patients both alternatives, describing different future symptom scenarios depending on outcome. However, the other stance is to advocate a biological rationale indicating that leaving a tumour in situ involves a risk of mutation that results in metastases and thereby worsens the prognosis. In addition, an unsuccessful treatment with cystostatics or radiotherapy can jeopardize operability, which may also adversely affect survival. Before having valid data, the best possible conjecture is that organ preservation decreases survival in an unknown percentage of subjects. Taking this stance, a randomized study comparing radical cystectomy with any organ preservation strategy would be unethical for

**Table 5.** Sexually related symptoms among men during previous 6 months, occurrence and distress, age-adjusted relative risks

Variable	Controls (n = 209)	Patients with reservoir (n = 38)	Patients with conduit (n = 127)
<i>Sexual activity/sexuality</i>			
Sexual desire less than once a month, n/total n (%)	105/197 (53)	16/35 (46)	69/117 (59)
Relative risk for patients vs. controls	1.0	1.1 (0.8–1.7)	1.2 (0.9–1.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.2 (0.8–1.8)
No intercourse, n/total n (%)	94/182 (52)	28/36 (78)	84/99 (85)
Relative risk for patients vs. controls	1.0	2.0 (1.4–2.7)	1.7 (1.5–2.1)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.1 (0.9–1.3)
No orgasm, n/total n (%)	74/187 (40)	19/33 (58)	72/107 (67)
Relative risk for patients vs. controls	1.0	2.0 (1.3–3.0)	1.8 (1.4–2.2)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.1 (0.8–1.5)
Little or no orgasmic pleasure, n/total n (%) <sup>b</sup>	28/118 (24)	6/15 (40)	12/38 (32)
Relative risk for patients vs. controls	1.0	2.1 (1.0–4.7)	1.4 (0.8–2.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.8 (0.3–2.0)
Low satisfaction with sexual aid presently used, n/total n (%) <sup>c</sup>	7/19 (37)	7/12 (58)	12/24 (50)
Relative risk for patients vs. controls	1.0	1.1 (0.5–2.3)	1.3 (0.7–2.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.9 (0.5–1.8)
<i>Erectile function</i>			
Erection moderately or substantially insufficient, n/total n (%)	86/196 (44)	33/35 (94)	102/112 (91)
Relative risk for patients vs. controls	1.0	2.7 (2.0–3.7)	2.2 (1.8–2.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.9 (0.8–1.1)
<i>Other problems during sexual activity</i>			
No ejaculate during orgasm, n/total n (%) <sup>b</sup>	8/139 (6)	12/12 (100)	26/27 (96)
Relative risk for patients vs. controls	1.0	17.4 (8.9–34.1)	25.2 (10.5–60)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.9 (0.9–1.1)
<i>Symptom distress in whole group</i>			
Little or no satisfaction with present sexuality/sexual life, n/total n (%)	46/176 (26)	24/31 (77)	63/96 (66)
Relative risk for patients vs. controls	1.0	3.2 (2.2–4.6)	2.5 (1.9–3.4)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.9 (0.7–1.1)
No or low interest in sex, n/total n (%)	98/196 (50)	14/35 (40)	73/117 (62)
Relative risk for patients vs. controls	1.0	1.1 (0.7–1.7)	1.3 (1.1–1.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	1.2 (0.8–1.9)
Moderate or substantial effect on sex life of urinary/urostomy symptoms, n/total n (%)	6/205 (3)	14/36 (39)	30/124 (24)
Relative risk for patients vs. controls	1.0	8.8 (4.1–18.7)	7.2 (3.6–14.1)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.7 (0.4–1.3)
Moderate or substantial effect on sex life of bowel problems, n/total n (%)	5/209 (2)	1/37 (3)	4/122 (3)
Relative risk for patients vs. controls	1.0	1.2 (0.1–12.8)	1.4 (0.4–5.1)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.4 (0.05–5.3)
Moderate or substantial distress if erectile dysfunction persists, n/total n (%)	63/190 (33)	19/32 (59)	38/99 (38)
Relative risk for patients vs. controls	1.0	1.7 (1.1–2.6)	1.1 (0.8–1.6)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.7 (0.5–1.1)
Moderate or substantial distress if experienced sexual limitations persists, n/total n (%)	53/190 (28)	17/33 (32)	31/105 (30)
Relative risk for patients vs. controls	1.0	1.5 (1.0–2.4)	1.0 (0.7–1.5)
Relative risk for conduit vs. reservoir <sup>a</sup>		1.0	0.7 (0.4–1.1)

<sup>a</sup> The analysis was restricted to patients with a maximum age of 76.

<sup>b</sup> The analysis was restricted to sexually active men.

<sup>c</sup> The analysis was restricted to men using a sexual aid.

**Table 6.** Well-being and energy level, anxiety, and depression level during previous 6 months, age and sex-adjusted relative risks

Variable	Controls (n = 310)		Patients with reservoir (n = 55)		Patients with conduit (n = 168)	
Low psychological well-being (1–5/7), n/total n (%)	118/300	(39)	33/53	(62)	78/161	(48)
Relative risk for patients vs. controls	1.0		1.6 (1.2–2.2)		1.3 (1.0–1.6)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.8 (0.6–1.1)	
Low physical well-being (1–5/7), n/total n (%)	168/297	(57)	34/53	(64)	106/161	(65)
Relative risk for patients vs. controls	1.0		1.3 (1.0–1.7)		1.2 (1.0–1.4)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.0 (0.8–1.3)	
Low energy level (1–5/7), n/total n (%)	206/297	(69)	42/52	(81)	136/161	(85)
Relative risk for patients vs. controls	1.0		1.3 (1.0–1.5)		1.2 (1.1–1.4)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.0 (0.8–1.1)	
High anxiety level (3–7/7), n/total n (%)	60/298	(20)	14/53	(26)	31/160	(19)
Relative risk for patients vs. controls	1.0		1.5 (0.9–2.6)		1.0 (0.7–1.5)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		1.0 (0.6–1.8)	
High depression level (3–7/7), n/total n (%)	105/301	(35)	28/53	(53)	63/159	(40)
Relative risk for patients vs. controls	1.0		1.6 (1.1–2.3)		1.2 (1.0–1.6)	
Relative risk for conduit vs. reservoir <sup>a</sup>			1.0		0.8 (0.5–1.1)	

<sup>a</sup> The analysis was restricted to patients with a maximum age of 76.

the two thirds of patients in the present study who report unwillingness to compromise survival in order to diminish the postoperative symptom burden, even if survival was compromised in only 1% of the subjects.

Our study describing a before-after situation is observational, and confounding is certainly an issue in the comparisons between patients with conduit and patients with reservoir [27, 28]. In the complete groups, moderate or much symptom distress from diarrhoea and defecation urgency, respectively, was more prevalent in the conduit group than in the reservoir group. The symptoms were not related to age, and adjusting for age did not alter the results. The same was true, somewhat unexpectedly, of preoperative radiotherapy regardless of dose. However, minor nonsignificant differences between patients preoperatively treated with 40 and 20 Gy irradiation were detected. We observed a large difference in urine leakage in favour of a conduit, but no difference was found concerning odour. Other urinary variables, as well as sexual function, were not altered by the type of urinary diversion. It is clear from our study that differences concerning the two types of urinary diversion are restricted to a few outcome variables.

We used an anonymous questionnaire answered in the home environment. This method probably results in fewer investigator-derived errors than, for example, a personal interview or an identifiable questionnaire [27, 28]. One disadvantage of this technique is the impossibility of supplementing the answers when necessary; no data could be linked to individual patients. Sweden maintains population-based registers

that allow us to avoid potential problems of selection. Great efforts were made to minimize the frequency of non compliance to diminish any resulting bias [28]. We restricted the material to patients operated on at least 3 years before completing the questionnaire in order to exclude transient postoperative effects and not disturb patients who turn out to be short-term survivors. Most deaths from urinary bladder cancer occur within the first 3 years after diagnosis [29].

Although the situation for men and women undergoing cystectomy in seriously impaired due to changed bowel function, a dissatisfactory sexual life, frequent urinary tract infections and a feeling of decreased attractiveness (due to a visible urinary diversion) the conditions in patients with urinary diversion have been poorly documented and analysed. Intensified pre- and postoperative information, psychological support [30], as well as measures to prevent and relieve chronic distressful symptoms, may better the situation for the cystectomized patient. Reasonably less traumatic surgery, sparing nerves and with careful dissection, and alternative urinary diversion with orthotopic bladder reconstruction, can further improve the situation. However, in our search for means to diminish symptom occurrence, we have to consider the fact that only a minority of women and men are willing to accept a deviation from the treatment thought to provide the best prospects for survival.

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