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ORIGINAL RESEARCH ARTICLE

Health-related quality of life prior to and 1 year after radical cystectomy evaluated with FACT-G and FACT-VCI questionnaires

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ABSTRACT

Objective: The aim of this study was to investigate health-related quality of life (HRQoL) before and 1 year after radical cystectomy in relation to age and gender.

Methods: This prospective study involves 112 men and 40 women with bladder cancer treated with radical cystectomy between 2015 and 2018. HRQoL was assessed preoperatively and 1 year post-surgery through Functional Assessment of Cancer Therapy Scale – General (FACT-G) and Functional Assessment of Cancer Therapy Scale – Vanderbilt Cystectomy Index (FACT-VCI) questionnaires. The median age of the 152 patients was 71.5 years.

Results: Preoperatively, emotional and functional well-being were negatively affected. Physical, emotional and functional well-being presented higher values 1 year after surgery compared to before radical cystectomy, that is, better HRQoL. Social well-being showed a reduction, especially regarding closeness to partner and support from family. Men and women were equally satisfied with their sex life before radical cystectomy, but less so 1 year after, where men were less satisfied compared to women. Additionally, one out of five patients reported that they had to limit their physical activities, were afraid of being far from a toilet and were dissatisfied with their body appearance after surgery.

Conclusions: Recovery regarding HRQoL was ongoing 1 year after radical cystectomy. Patients recovered in three out of four dimensions of HRQoL, but social well-being was still negatively affected 1 year after treatment. Sexual function after radical cystectomy was exceedingly limited for both men and women. An individual sexual rehabilitation plan involving the couple with special intention to encourage intimacy, might not only improve sexual life but also have a positive effect on social well-being as a consequence.

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Introduction

Radical cystectomy with urinary diversion and pelvic lymph node dissection is the standard treatment not only for muscle-invasive bladder cancer stage T2–T4 N0 M0 with curative intent but also for patients with non-muscle-invasive bladder cancer with a high risk of progression [1]. Such surgery is extensive, involving several different organ systems (urinary tract, lymphatic tissue, bowel and internal reproductive organs). The most common type of urinary diversion used is ileal conduit, and today, only a minority of patients receive an orthotopic neobladder or a continent cutaneous pouch [1]. When interviewing patients with urinary diversion, it emerges that coping with new daily routines and regaining independence, self-acceptance and confidence are significant long-term challenges [2–4]. Quality of life (QoL) is a complex concept meaning different things to various individuals. The World Health Organization defines the concept as 'the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment' [5]. Health-related quality of life (HRQoL) is often used to distinguish QoL affected by disease or treatment from QoL in general. In studies about HRQoL among patients treated with radical cystectomy, several questionnaires and instruments have been used, though not always externally validated [6]. Research has so far compared HRQoL between ileal conduit and orthotopic neobladder and between robot-assisted and open surgery [7–11]. However,

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with an increased proportion of older patients being subjected to radical cystectomy, there is a lack of studies measuring HRQoL pre- and postoperatively and investigating the association of HRQoL and age in a bladder cancer population [12,13]. Similarly, gender-specific assessments of HRQoL have not been taken into account so far, although differences between genders might be present [14]. The aim of this study was therefore to investigate radical cystectomy HRQoL and additional radical cystectomy related concerns before and 1 year after radical cystectomy in relation to age and gender.

Material and methods

Study design and population

A longitudinal, descriptive and comparative study involving patients treated with radical cystectomy due to bladder cancer in Sweden from 2015 to 2018 was undertaken. The patients were treated in six different hospitals (Malmö, Gothenburg, Stockholm, Uppsala/Örebro, Helsingborg and Linköping). The Functional Assessment of Cancer Therapy Scale – General (FACT-G) was distributed preoperatively at each cystectomy unit before surgery. A follow-up questionnaire (Functional Assessment of Cancer Therapy Scale – Vanderbilt Cystectomy Index [FACT-VCI]) was distributed by the Regional Cancer Centre (RCC) South 12 months after cystectomy. The FACT-VCI questionnaire was distributed to all patients subjected to radical cystectomy in Sweden, according to the Swedish National Registry of Urinary Bladder Cancer (SNRUBC). In accordance with patients' preferences, responses could be submitted electronically or by ordinary mail to the RCC South, Lund, Sweden. Patients who completed both questionnaires (pre- and post-surgery) were included in this study (n = 152; 112 men and 40 women).

HRQoL questionnaires

HRQoL was assessed by using FACT-G questionnaire before radical cystectomy. The FACT-G is a validated questionnaire that aims to measure the following dimensions of HRQoL: physical, social, emotional and functional well-being. It can be used for evaluating HRQoL among persons with various cancer diagnoses and treatments. FACT-G consists of 27 items, and each item is scored on a Likert scale: zero = not at all, one = a little bit, two = somewhat, three = quite a bit and four = very much. The domains of physical (seven items), functional (seven items) and social well-being (seven items) can each be summarised with a range from 0 to 28, and the domain of emotional well-being (six items) with a range from 0 to 24, where a higher value indicates better HRQoL [15,16].

The validated FACT-VCI questionnaire is based on the FACT-G, including supplemental questions regarding 17 items about additional concerns related to urinary diversion [17,18]. FACT-VCI contains items from three other questionnaires: FACT – Bladder Cancer, FACT – Colorectal and the Functional Assessment of Incontinence Therapy – Urinary. Similar to the FACT-G, the FACT-VCI uses scores: zero = to four and higher scores indicate better HRQoL [19]. One question is male-specific and therefore not included in the summarised score. Both FACT-G and FACT-VCI have been translated into Swedish, and a validation process showed that the Swedish versions have the same validity and reliability as the original versions [18].

Statistical methods

Before analysing the sums of the FACT-G and the FACT-VCI, 12 items in FACT-G and further 10 items about additional concerns that were part of FACT-VCI were transformed, meaning that all questions were valued equally, and that higher scores indicated better HRQoL [15,16]. All questions in the FACT-G and the FACT-VCI were analysed on an aggregated level, resulting in a sum score for the different dimensions. Furthermore, in the additional concerns (FACT-VCI), 15 questions out of 17 were aggregated, according to the scoring guidelines [20]. Both questionnaires (FACT-G and FACT-VCI) were also analysed separately for each question. All data were subjected to descriptive analyses. Pair-wise comparisons were performed with a non-parametric method using the Wilcoxon rank-sum test. Age groups were divided with the median age as a cut-off point (71.5 years). Nominal data were compared by applying a Chi-square test, and other variables with Mann–Whitney U-test. A $p < 0.05$ was regarded as significant. IBM SPSS statistics version 26 was used for all analyses.

Ethical approval

This study was registered (ISRCTN99427820) and approved by the Research Ethics Board of Lund University, Sweden (Reg. No. 2014/832).

Results

The median age of the 152 patients was 71.5 (range 46–87) years. Information about patient characteristics is presented in Table 1, including distributions in gender and age groups. Neoadjuvant chemotherapy and continent reconstructions were less often offered to older patients.

Preoperatively, emotional and functional well-being had the lowest scores, especially questions about QoL right now, nervousness, worries, sleep and acceptance of the illness. Postoperatively, social well-being showed a reduction compared to preoperative values, particularly questions about satisfaction with sexual life, closeness to and support from family and friends, and closeness to the partner (Tables 2 and 3). Physical, emotional and functional well-being presented higher values, which means improved HRQoL, postoperatively. Regarding physical well-being, issues concerning pain, nausea and feeling sick were significantly improved 1 year after radical cystectomy. Emotional well-being, including feelings of sadness, nervousness, concerns about dying or progression of the disease and satisfaction how to cope with the illness, was also improved postoperatively. Scores on functional well-

Table 1. Baseline characteristics distributed by gender and age groups.

	Total *n* = 152	Women *n* = 40	Men *n* = 112	Younger group <71.5 years *n* = 76	Older group >71.5 years *n* = 76
Age, median	71.5	69.5	72.5	66.0	76.0
Range	46–87	46–87	46–84	46–71	72–87
ASA score, *n* (%)					
≤2	116 (78)	34 (87)	82 (75)	61 (81)	55 (74)
>2	33 (22)	5 (13)	28 (25)	14 (19)	19 (26)
p		0.083*		0.061*	
BMI, median	25.7	24.5	26.0	25.9	25.5
Range	16.4–38.2	16.4–38.2	18.5–35.8	18.5–38.2	16.4–35.4
p		0.072*		0.398*	
Stage, *n* (%)					
≤cT1	40 (26)	12 (30)	28 (25)	22 (29)	18 (24)
cT2	77 (51)	22 (55)	55 (49)	36 (48)	41 (54)
cT3	25 (16)	5 (13)	20 (18)	14 (18)	11 (14)
cT4	9 (5.9)	1 (2.5)	8 (7.1)	3 (3.9)	6 (7.9)
cTX	1 (0.7)	-	1 (0.9)	1 (1.4)	0 (0)
p		0.400*		0.926*	
Clinical lymph node status, *n* (%)					
cN0	131 (86.2)	36 (90)	95 (84)	64 (84)	67 (88)
cN+	17 (11.2)	4 (10)	13 (12)	9 (12)	8 (11)
cNX	4 (2.6)	-	4 (3.6)	3 (3.9)	1 (1.3)
p		0.468**		0.109**	
Distant metastases, *n* (%)					
M0	150 (99)	39 (98)	111(99)	74 (97)	76 (100)
M1a	2 (1.3)	1 (2.5)	1 (0.9)	2 (2.6)	0 (0)
p		0.458**		0.155**	
Neoadjuvant chemo, *n* (%)					
Yes	63 (42.0)	18 (45)	45 (41)	47 (62)	16 (22)
No	87 (58.0)	22 (55)	65 (59)	29 (38)	58 (78)
p		0.653**		**<0.001****	
Type of surgery, *n* (%)					
Open	118 (78)	28 (70)	90 (80)	59 (78)	59 (78)
Robot assisted	34 (22)	12 (30)	22 (20)	17 (22)	17 (22)
p		0.177**		1.0**	
Urinary diversion, *n* (%)					
Ileal conduit	134 (88)	36 (90)	98 (88)	60 (79)	74 (97)
Continent cutaneous diversion	2 (1.3)	2 (5)	0	2 (2.6)	0
Orthotopic neobladder	16 (11)	2 (5)	14 (12)	14 (18)	2 (2.6)
		0.601*		**<0.001***	
Urethrectomy					
n (%)	44 (29)	29 (73)	15 (13)	28 (37)	16 (21)
p		**<0.001****		0.036**	
Hospital postoperative stay (days)					
Median	12	12	12	12	13
Range	4–81	5–56	4–81	4–27	4–81
p		0.678*		0.125*	

*Mann–Whitney *U*-test.

**Chi-square test.

being, such as ability to enjoy life, acceptance of illness, sleeping, QoL right now and enjoying things for fun, were improved 1 year after surgery.

Comparing HRQoL between age groups, the younger group had lower physical well-being preoperatively compared to the older group ($p < 0.001$); postoperatively, however, there were no differences in any dimension of well-being. There were no significant differences between men and women when comparing HRQoL in any dimensions either preoperatively (FACT-G) or postoperatively (FACT-VCI).

Regarding the questions about additional concerns postoperatively, the topics that emerged as most bothersome were limited sexual activity, physical and social activities, and fear of being far from a toilet (Table 4). Likewise, interest in sex

Table 2. Total HRQoL sum scores, and percentages of max score within all dimensions before and after surgery. Higher scores indicate better HRQoL.

	Preoperatively (FACT-G) *n* = 152	Postoperatively (FACT-VCI) *n* = 152	Preoperatively (FACT-G) Younger group <71.5 years	Preoperatively (FACT-G) Older group >71.5 years	Postoperatively (FACT-VCI) Younger group <71.5 years	Postoperatively (FACT-VCI) Older group >71.5 years
Physical well-being						
Mean (SD)	21.9 (5.4)	23.4 (4.4)	20.2 (5.7)	23.5 (4.5)	23.5 (4.8)	23.2 (4.0)
Percent of max score	78	84	72	84	84.0	83
Max score: 28						
p	**0.005***		**<0.001****		0.282**	
Social well-being						
Mean (SD)	23.0 (4.9)	21.5 (5.3)	23.2 (3.7)	22.8 (6.0)	21.2 (5.0)	21.7 (5.6)
Per cent of max score	82	77	83	81	76	78
Max score: 28						
p	**<0.001***		0.524**		0.351**	
Emotional well-being						
Mean (SD)	16.7 (4.6)	19.1 (4.3)	16.5 (4.6)	16.9 (4.6)	18.9 (4.5)	19.3 (4.2)
Per cent of max score	70	80	69	70	79	80
Max score: 24						
p	**<0.001***		0.696**		0.523**	
Functional well-being						
Mean (SD)	17.9 (5.4)	20.2 (5.6)	17.4 (5.2)	18.4 (5.6)	20.8 (5.4)	19.6 (5.8)
Per cent of max score	64	72	62	66	74	70
Max score: 28						
p	**<0.001***		0.134**		0.113**	
Additional concerns						
Mean (SD)		44.6 (8.9)			45.1 (7.9)	44.0 (10.0)
Per cent of max score		74			75	73
Max score: 60						
p					0.468**	

*Wilcoxon signed ranks sum test.

**Mann–Whitney *U*-test.

and body appearance were concerns. Even the ability to have and maintain an erection affected majority of the men (104) who answered these questions, with 93 men (89%) reporting a poor erectile function and only three men (3%) reporting quite a bit or very much function.

Comparing men and women regarding additional concerns postoperatively, there were no differences except for the two items about sexuality, that is, limited sexual activity and interest in sex. The proportion of men interested in sex was 50% compared to 17% of the women, and men had also limited their sexual activity to a larger extent than women, 86% versus 51%, respectively (Table 5).

When comparing age groups, the proportion of younger patients who were interested in being sexually active was 49% ($n = 37$) compared to 28% ($n = 21$, $p = 0.013$) among the older patients. No further differences were found between age groups regarding the questions about concerns postoperatively.

Discussion

This study identified both improved and reduced HRQoL 1 year after radical cystectomy compared to baseline preoperatively. The persons in this study improved their physical, emotional and functional well-being 1 year after radical cystectomy compared to just before surgery, but social well-being was still impaired, and sexual concerns increased. Preoperatively, the most affected parts of HRQoL were emotional and functional well-being, for example, QoL right now, sadness, sleep, nervousness, fear of dying and worries. This is probably a normal reaction when facing a cancer diagnosis and treatment including surgery, and the preoperative assessment was performed during a period of newly diagnosed disease and planned treatment with high impact, all this related to worrying, that is, a time of low HRQoL. It is not unusual with depression and even thoughts of suicide before comprehensive cancer surgery [21,22]. In clinical praxis, it can therefore be of value to use a screening instrument for depression to identify persons at risk. It is obvious that there is a general need for emotional and functional support preoperatively. For instance, there is evidence from several randomised trials [23] supporting that preoperative educational interventions can reduce anxiety, and there might also be pharmacological options. In summary, it is important with a holistic perspective in the preoperative period to optimise the patients' emotional and functional well-being.

Decreased social support from friends, family and partner 1 year after surgery has also been confirmed by other studies [2,3]. The feeling of reduced support can depend on perceptions that the patient appears healthy and recovered, from the perspective of family and friends. However, for the patient, the recovery process and acceptance of the new circumstances may take longer. Thus, it is a challenge to understand the need for further support in social well-being in order for improvement to continue as long as needed during the recovery process. It would have been valuable to study if social well-being was associated with living together with someone or not, but

Table 3. Responses to specific questions within all dimensions, with proportions in per cent. Numbers in bold figures show negative outcomes.

	Preoperative (FACT-G)			Postoperative (FACT-VCI)			*p**
	Not at all/a little bit (0–1) (%)	Some what (2) (%)	Quite a bit/ very much (3–4) (%)	Not at all/a little bit (0–1) (%)	Some what (2) (%)	Quite a bit/ very much (3–4) (%)	
Physical well-being							
I have a lack of energy	48	32	**20**	55	25	**20**	0.084
I have nausea	85	10	**4.7**	97	2	**0.7**	**<0.0001**
Because of my physical condition, I have trouble meeting the needs of my family	66	19	**16**	66	22	**12**	0.953
I have pain	75	15	**10**	84	12	**4**	**0.019**
I am bothered by side effects of the treatment	62	22	**16**	74	15	**11**	0.076
I feel ill	76	14	**11**	87	8	**5.3**	**0.003**
I am forced to spend time in bed	92	5.3	**2.7**	95	3.9	**0.7**	0.191
Social well-being							
I feel close to my friends	**5.4**	6.7	88	5.4	**12**	83	**0.045**
I get emotional support from my family	**3.3**	2.6	94	6	**9.3**	85	**0.001**
I get support from my friends	**4.0**	9.4	87	7.9	**16**	76	**0.001**
My family has accepted my illness	**3.4**	6.8	90	2.7	**3.3**	94	0.133
I am satisfied with family communication about my illness	**4.7**	3.4	92	3.4	**10**	87	0.410
I feel close to my partner (or the person who is my main support)	**9.0**	0	91	4.2	**6.2**	90	**0.033**
I am satisfied with my sex life	**38**	25	37	73	**11**	16	**<0.0001**
Emotional well-being							
I feel sad	49	35	**16**	69	24	**6.6**	**<0.0001**
I am satisfied with how I am coping with my illness	**11**	28	60	**9.9**	12	78	**0.003**
I am losing hope in the fight against my illness	83	12	**5.3**	88	7.9	**4.6**	0.058
I feel nervous	55	25	**20**	79	14	**7.2**	**<0.0001**
I worry about dying	73	17	**9.8**	82	8.6	**9.2**	**<0.0001**
I worry that my condition will get worse	55	28	**17**	69	16	**15**	**0.003**
Functional well-being							
I am able to work (include work at home)	**11**	23	66	**8.1**	18	74	0.101
My work (include work at home) is fulfilling	**13**	21	66	**11**	20	69	0.347
I am able to enjoy life	**14**	21	65	**9.3**	15	75	**0.025**
I have accepted my illness	**16**	27	57	**8.7**	10	81	**<0.0001**
I am sleeping well	**19**	20	61	**8**	17	75	**<0.0001**
I am enjoying the things I usually do for fun	**14**	25	62	**9.4**	18	73	**0.002**
I am content with the quality of my life right now	**26**	24	50	**15**	20	65	**<0.0001**

*Wilcoxon signed rank-sum test.

unfortunately such data were not available. A qualitative study from 2019 showed that conversations with other patients in the same situation provided highly valued support, and that a patient association could be an example of an opportunity for such support [4].

The negative influence on sexual function 1 year after radical cystectomy affected both men and women, but men to a higher extent, as measured with the FACT-VCI. However, the internal dropout of these questions was considerable. This may suggest that sexuality is not relevant to all patients or that some patients may be uncomfortable discussing this topic. Men had a greater wish for sex and more limitations compared to women. This corresponds to the findings in a review from 2018, which showed that 46–59% of the women reported sexual dysfunction after radical cystectomy compared to 80–90% of the men [21]. In the current study, only 3% of the men declared the ability to have an erection, and 8% had partial erectile function. There is no corresponding question about erectile tissue in women reflecting the impact of surgery on nerves, blood vessels or altered anatomy after radical cystectomy. Sexual function in women who have undergone radical cystectomy is also less investigated [24]. Voigt et al. [24] point out a significant gender bias in the approach to sexual function for men and women. As the bladder cancer population is skewed from the outset, with a high proportion of men at an old age at diagnosis most research results are biased. Considering the extent of the operation, one cannot expect the sexual function to be like the preoperative level. It is consequently important that sexuality is discussed with both women and men before and after radical cystectomy, not only to understand anatomical and physiological changes and find strategies for sexual recovery but also as a basis for evaluating sexuality-preserving measures during radical cystectomy. For example, refraining from urethrectomy (performed in 73% of females and 13% of males in the current study) or to consider nerve-sparing surgery (26% in the current study) for non-muscle invasive disease with decreased

Table 4. Additional concerns 1 year after radical cystectomy. Numbers in bold figures show negative outcomes.

	Not at all/a little bit	Somewhat	Quite a bit/very much
	n (%)	*n* (%)	*n* (%)
I am losing weight	135 (89)	9 (6)	**7 (4.6)**
I have diarrhoea	131 (87)	11 (7.3)	**8 (5.3)**
I have trouble controlling my urine	131 (89)	12 (8.1)	**5 (3.4)**
My condition wakes me up at night	105 (70)	26 (17)	**19 (13)**
I am embarrassed by my condition	111 (75)	25 (17)	**13 (8.7)**
Caring for my urinary condition is difficult	125 (84)	16 (11)	**8 (5.4)**
I have to limit my social activity because of my condition	93 (62)	35 (23)	**23 (15)**
I have to limit my physical activity because of my condition	86 (57)	34 (23)	**30 (20)**
I have to limit my sexual activity because of my condition[a]	19 (14)	13 (9.4)	**107 (77)**
I am afraid to be far from a toilet	100 (66)	20 (13)	**31 (21)**
I have control of my bowels	**20 (13)**	17 (11)	114 (76)
I have a good appetite	**10 (6.6)**	17 (11)	124 (82)
I am content with the appearance of my body	**33 (22)**	41 (27)	77 (51)
I am comfortable discussing my condition with friends	**17 (11)**	15 (10)	118 (79)
I am satisfied with my urinary condition	**7 (4.6)**	27 (18)	117 (77)
I am interested in sex[b]	**49 (35)**	33 (24)	58 (41)
(For men only) I am able to have and maintain an erection[c]	**93 (89)**	8 (7.7)	3 (2.9)

Missing: [a]13, [b]12 and [c]8.

oncological risk in order to increase the possibilities for sexual recovery. Another example of such sexuality-preserving measures during radical cystectomy is vaginal-sparing. The currently available evidence on the effect of sexual function after orthotopic neobladder versus ileal conduit [8] and use of robotic-assisted radical cystectomy is less clear [25]. Nonetheless, in the recovery process, it is important to involve and encourage patients and their partner with special intension to intimacy in order to improve sexual life and maybe also get a secondary positive effect on social well-being.

Improvements in three out of four dimensions of HRQoL imply that the recovery process was ongoing 1 year after surgery, and that emotional and functional well-being improved most, which correlates with findings in two recent studies [3,26]. In contrast, there are some areas that seem to cause concerns for the patients; for instance, one out of five was dissatisfied with their urinary diversion and was not content with their body appearance. Decision regret related to urinary diversion choice has also been negatively associated with HRQoL [27]. Furthermore, there seems to be a feeling of insecurity among the patients, making 33% afraid of being far from a toilet, possibly a reason for the limitation of physical and social activities. Education and support of the urinary diversion care and regular follow-up is an important issue to increase the sense of security and participation in social life.

The results in this study highlight the importance of specific questions to sort out the patients' concerns in daily life, during both the pre- and postoperative period. FACT-G and FACT-VCI are examples of questionnaires that contain such questions. In addition, the inclusion of patients from six population-based cystectomy units in the current study is a strength compared to previous studies. The sum score may be helpful to demonstrate exposed areas to be focused on, but those areas must be analysed in depth with detailed questions. This will help ensure

Table 5. Sexual life reported by women and men in per cent within each group.

	Women *n* = 40			Men *n* = 112		
	Not at all/ a little bit	Somewhat	Quite a bit/ very much	Not at all/a little bit	Somewhat	Quite a bit/very much
Before surgery						
I am satisfied with my sex life,[a] *n* (%)	6 (29)	6 (29)	9 (43)	31 (41)	18 (24)	27 (35)
p-value (differnece between women and men)			0.47**			
After surgery						
I am satisfied with my sex life,[b] *n* (%)	12 (52)	4 (17)	7 (31)	64 (79)	7 (8.6)	10 (12)
p-value (differnece between women and men)			**0.004****			
I have to limit my sexual activity because of my condition,[c] *n* (%)	10 (29)	7 (20)	18 (51)	9 (8.6)	6 (5.8)	89 (86)
p-value (differnece between women and men)			**<0.0001****			
I am interested in sex[d] *n* (%)	17 (47)	13 (36)	6 (17)	32 (31)	20 (19)	52 (50)
			0.001**			

Missing for women: [a]=19, [b]=17, [c] =5 and [d]= 4; missing for men: [a]=36, [b]=31, [c]=8 and [d]= 8.

**Chi-square test.

person-centred care and could be a quality indicator for providers. Still, patients experienced the meeting with the clinician as often focusing more on the physical aspects and on cancer surveillance than on individual needs [2]. The patients in Paterson et al.'s study reported a lack of opportunities to discuss problems like psychological issues, sexual and body functions [2]. A structured follow-up routine would facilitate to provide an adequate support during the recovery process. In summary, the present study showed that sensitive issues such as sexuality, body image and social well-being are the most bothersome and therefore need to be focused on and developed during future research.

Limitations

This study consists of register data and is hence a non-stratified sample, and an external dropout rate is unknown. Each participating hospital distributed FACT-G questionnaires preoperatively and the responding proportion is not known. Furthermore, there were some internal dropouts (missing values) in the FACT-G questionnaire preoperatively and in the questions about sexual issues. FACT-VCI includes a specific question addressed to men about erection, but there is no equivalent question for women, further strengthening the gender bias when comparing men and women regarding this aspect. Similarly, the results are also affected by the unequal gender distribution of the bladder cancer population. Despite the different group sizes, we found it important to perform comparisons between men and women, but the results must be taken as trends, and more research is needed to explore differences related to gender. Another limitation is that frail and/or older persons and those not acquainted with the Swedish language were not represented in the study. The preoperative assessment was performed during a period of newly diagnosed disease and planned treatment with high impact on HRQoL. It is therefore difficult to evaluate improvement 1 year after surgery; nonetheless, it is clear that some issues are connected to worsened HRQoL after surgery. Although it is not possible to collect patient-based data for comparison, age- and gender-matched population-based data could be an option.

Conclusion

Considering the extent of advanced bladder cancer disease, treatment and surgery, the HRQoL recovery process is still ongoing 1 year after radical cystectomy. Three out of four dimensions of HRQoL (physical, emotional and functional well-being) showed a positive recovery process. However, the dimension of social well-being, especially in terms of closeness to and support from family and friends and in terms of satisfaction with sexual life, is still negatively affected 1 year after radical cystectomy, and sexual function is severely limited in both men and women. An individual sexual rehabilitation plan involving the couple with for example special intension to encourage intimacy is desirable, as improved sexual life might have a positive effect on social well-being as well.

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Disclosure statement

None of the authors have any conflicts of interest to report.

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