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Original Article

Informing patients about the negative effect of nephrectomy on sexual function

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ABSTRACT

Objective: The quality-of-life concept has increasingly gained attention, but an important aspect has been neglected, which is the sexual function of patients with kidney cancer after surgery. The aim of this study was to explore the impact of nephrectomy on sexual function in patients with kidney cancer and the information patients received with this regard.

Material and methods: We conducted a retrospective study of patients who underwent nephrectomy or nephro-ureterectomy within a 5-year period at the Department of Urology, Odense University Hospital, Denmark. Among 310 patients having undergone surgery, 226 were still alive and eligible for participation. Their records were reviewed, and a validated questionnaire concerning their sex life was mailed to them. All participants were invited to take part in a semi-structured interview in person or by phone.

Results: Of 154 former patients who replied, 95 were men (mean age, 66 years, range 37–89), 59 were women (mean age 63 years, range 26–87). A significant difference was observed regarding problems with sexual relationships prior to operation compared after (P<0.0001). Seven patients (5%) had been informed about potential effects and changes in their sex life following operation. Both male and female participants were worried about their sex life (61.4%). Among sexually active male responders, 54.7% reported having some degree of erectile dysfunction.

Conclusion: Patients experience significantly more problems in their sexual relationships after surgery. Very few were informed about this, showing the need to offer sex counselling before surgery. More research is required to fully comprehend the magnitude of the problem.

Keywords: Erectile dysfunction; kidney cancer; libido; nephrectomy; sexuality; quality of life, patient information.

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Introduction

The number of newly diagnosed patients with kidney cancer has increased,[1,2] and more than 50% of renal cell cancer (RCC) cases are detected incidentally when imaging is used to investigate various non-specific abdominal symptoms. In parallel, the survival has improved within this group of patients in Denmark.[3,4] Thus, the quality-of-life (QOL) concept has increasingly gained attention. Most extant studies of QOL issues in patients with kidney cancer having undergone nephrectomy focus on survival and surgical outcomes, for example, parameters such as the length of hospital stay, surgical complications, and renal function,[5] but ignore an essential aspect of QOL, that is, sexuality.

Sexuality and intimacy are important aspects of life that can be affected by physiological, psychological, and social factors, not only by cancer and its treatment.[6-8] Cancer in general and cancer affecting the reproductive organs in particular affects patients' sex life.[7,9] However, to the best of our knowledge, no studies have so far included patients with kidney cancer and examined this issue. We therefore have only sparse knowledge about the sexual function of this group of patients,

and further studies are required to evaluate the consequences of nephrectomy on sexuality.

Our aim was to investigate and evaluate whether there is a need for improvement of the information given to kidney cancer patients before and after surgery and if there is a necessity for sex counselling.

Material and methods

Participants

Potential participants for this cross-sectional, retrospective study were found using the *International Classification of Disease* (10th edition) (ICD10) diagnosis codes (DC64.9 and DC65.9) and operation codes (KKAC00, KKAC01, KKAC20, and KKAC21) combined with data from the Danish Central Person Registry. All operations had been performed at the Department of Urology, Odense University Hospital, Denmark, within a 5-year study period. None of the participants had received chemotherapy after surgery.

Patients who were still alive and had undergone surgery and had the correct diagnosis code after examination of the histology were eligible to participate. Patients' medical records were examined, and a questionnaire with an information letter and a stamped return envelope were mailed to eligible participants, who were given 6 weeks to answer. A reminder was sent to those who had not answered within 6 weeks. Furthermore, all patients were invited to take part in an interview.

Male responders' medical records were further examined to identify risk factors for sexual dysfunction, especially erectile dysfunction, to identify any association. Risk factors for male sexual dysfunction were defined as medically treated diabetes and/or hypertension, smoking, alcohol overuse (>14 units of 12 g alcohol per week), and overweight (body mass index >25.0 or described in the medical record as being overweight).

This quality-based study required no approval from the local scientific ethical committee. Participation in interviews and questionnaires was optional, and a positive reply from the patient was considered tantamount to informed consent.

Measures

A validated questionnaire for self-assessment of sexual function and vaginal changes after gynecological cancer, the Sexual function-Vaginal changes Questionnaire, was used,[10] but it was modified by the research group so that questions were relevant for both genders. General questions about sexual relationships, such as use of pharmaceutical assistance and sexual activity, were added to the first section. If a participant reported being sexually inactive before surgery, he or she was asked not to fill out the rest of the questionnaire, but merely to return that answer. At the end of the questionnaire, blank lines enabled participants to comment or elaborate freely. These additions were not validated.

Apart from questions concerning sexual function before and after surgery and information given, the questionnaire also contained items addressing sexual activity, interest, intimacy, and satisfaction. Each question was answered on a Likert scale ranging from "not at all" to "very much" or similar. In the statistical analysis and tables, these scales were merged to get a more clear-cut and not a ranked result.

An interview guide was constructed by a specialist in sexual medicine (FECSM-fellow European College of Sexual Medicine) as an extension of the questionnaire, with a focus on the information given and any changes in sex life after surgery. The interviews were semi structured with open-ended questions such as, "How has your libido changed since your operation?" The interviews were conducted as telephone interviews or in person at the hospital according to the patient's preference. The interviews were recorded on tape and analyzed afterwards.

Statistical analysis

To determine if there were any differences between numerical values, a one-way analysis of variance, t-test, was used. Binary outcomes were compared using a Fishers' exact test due to the small sample size. In this study, we used a two-sided p-value. A p-value <0.05 was considered statistically significant.

Throughout this paper, answers were analyzed without considering gender as only 17 women reported to have been sexually active before their surgery. Thus, the female subgroup would be too small for a separate evaluation which would invite type 2 errors.

Statistical analysis was preformed using the Statistical Analysis Software guide enterprise, Version 9.4 (SAS, North Carolina, United States of America).[11]

Results

Participants

Of 310 patients (188 men and 122 women) who had had nephrectomy or nephro-ureterectomy due to kidney cancer or kidney pelvic cancer, 61 (19.7%) [39 (64%) men and 22 (36%) women] had died since their operation, and 21 (6.8%) did not want to participate, which left 228 patients for analysis. Two (1 man and 1 woman) patients (0.9%) died before returning their questionnaires, leaving 226 participants eligible to answer and return the questionnaire. Of 154 (68.1%) patients who returned

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Table 1. Demographic data of responders

	Men	Women	p
Number (n)	88	55	
Age (years)			
Mean (range)	66 (37–89)	63 (26–87)	0.19
Time since operation (months)			
Mean (range)	26 (1–64)	32 (2–64)	0.10
Type of cancer (No, %)			
Kidney cancer	79 (89.8)	52 (94.5)	0.37
Kidney pelvic cancer	9 (10.2)	3 (5.5)	
Type of operation (No, %)			
Nephrectomy	77 (87.5)	52 (94.5)	0.25
Nephro-ureterectomy	11 (12.5)	3 (5.5)	
Sexually active before operation (No, %)			
Yes	53 (60.2)	17 (30.9)	0.001
No	35 (39.8)	38 (69.1)	
Due to lack of partner	3 (8.6)	8 (21.1)	
Due to partner disease	0	2 (5.3)	
Other reason	2 (5.7)	2 (5.3)	
No reason given	30 (85.7)	26 (68.4)	

the questionnaire, 11 (7 men and 4 women) did not wish to take part in the study, and they were excluded from further analysis.

We included 143 participants, 88 men (mean age 66 years, range 37-89) and 55 women (mean age 63 years, range 26-87). Basic clinical and demographic data are presented in Table 1. Sexual activity before operation differed markedly between the genders (p=0.0021) (Table 1). Among those who had not been sexually active before surgery, 17 (23.3%) reported reasons such as loss of partner, old age, or pain.

Questionnaire

We found a significant difference between participants who experienced sexual problems before compared to after surgery. The use of nonpharmaceutical and pharmaceutical assistance due to sexual problems before and after surgery also differed (Table 2). Thus, 11 (15.7%) participants reported loss of libido; 1 participant reported lack of energy as the reason and 1 male participant reported sexual performance anxiety the first months after surgery. Only 7 participants (5%) had been informed about potential sexual dysfunction as a surgical complication.

Worrying about impaired or lack of sex life was reported by 43 (61.4%) participants; of those, 24 (34.3%) were "worried" or "very worried" (Table 3). A total of 46 participants (86.8%) had been able to complete intercourse to some extent during the past month; of those, 12 (24.0%) only occasionally, 15 (30.0%) often, and 19 (38.0%) always. Forty-seven participants (88.7) reported to be able to reach orgasm; 15 (30.6%) occasionally, 12 (24.5%) often, and 20 (40.8%) always. Forty-nine (92.5%) participants reported sexual satisfaction; 9 (18.0%) a little, 17 (34.0%) quite a bit, and 23 (46.0%) very much. Only 2 participants (2.9%) experienced body image changes (Table 3).

Twenty participants (28.6%) experienced changes in their interest in intimacy, and 18 (25.7%) experienced changes in the frequency of intercourse since diagnosed with kidney cancer. Change in sexual interest since diagnosed with cancer was experienced by 19 (27.1%) participants, 1 (1.4%) of whom reported higher interest. Thus, the majority of the participants reported unchanged interest. Fourteen partners (20.0%) had experienced a change in interest in sexual relationships since diagnosis (Table 3).

Male participants

Fifty-three (60.2%) of the male participants had been sexually active before their operation (Table 1); 14 (26.4%) had had sexual problems before their operation compared with 28 (52.8%) who stated that they had sexual problems after their operation

Table 2. Results of questionnaire. The percentage is calculated from the total amount of responders who were sexually active before operation (n=70)

Question	Yes No. (%)	No No. (%)	Other No. (%)	Missing data No (%)
1. Problems with sexual relationships before operation	17 (24.3)	52 (74.3)	1 (1.4)	0
2. Usage of non-pharmaceutical assistance due to sexual problems	4 (5.7)	63 (90.0)	0	3 (4.3)
3. Usage of pharmaceutical assistance due to sexual problems	10 (14.3)	56 (80.0)	0	4 (5.7)
4. Information about potential problems with sexuality after the operation	7 (10.0)	57 (81.4)	2 (2.9)	4 (5.7)
5. Problems with sexual relationships after operation	34 (48.6)	36 (51.4)	0	0
6. Use of non-pharmaceutical assistance due to sexual problems	3 (4.3)	64 (91.4)	0	3 (4.3)
7. Usage of pharmaceutical assistance due to sexual problems	9 (12.9)	56 (80.0)	1 (1.4)	4 (5.7)
8. Feeling loss of sexual desire after operation	11 (15.7)	36 (51.4)	2 (2.9)	21 (30.0)

Table 3. Results of questionnaire. In general, the percentage is calculated from the total amount of responders who were sexually active before operation (n=70)

Question	Yes No (%)	No No (%)	Missing data No (%)
Section 2. During the past month			
1. Interest in close physical contact	67 (95.7)	3 (4.3)	0 (1.4)
2. Close physical contact with family and close friends	62 (88.6)	7 (10.0)	1 (1.4)
3. Interest in sexual relationship	61 (87.2)	8 (11.4)	1 (1.4)
4. Has a partner	63 (90.0)	6 (8.6)	1 (1.4)
5. Partner has been interested in sexual relationship *	57 (90.4)	3 (4.8)	3 (4.8)
6. Sexual relationships *	53 (84.1)	10 (15.9)	0
7. Problems with achieving an erection-partner/oneself **	29 (54.7)	24 (45.3)	0
8. Worrying about sex life/lack of sex life	43 (61.4)	24 (34.3)	3 (4.2)
9. Dissatisfied with sex life/lack of sex life	7 (10.0)	60 (85.7)	3 (4.2)
10. Dissatisfied with appearance	2 (2.9)	66 (94.3)	2 (2.9)
Section 3. During the past month **			
1. Able to complete intercourse	46 (86.8)	4 (7.5)	3 (5.7)
2. Reached orgasm	47 (88.7)	2 (3.8)	4 (7.5)
3. Feeling relaxed after sex	49 (92.5)	1 (1.9)	3 (5.7)
Section 4. In general			
1. Changes in interest in close physical contact since diagnosed with cancer	20 (28.6)	49 (70.0)	1 (1.4)
2. Changes in close physical contact with family and close friends since diagnosed with cancer	18 (25.7)	51 (71.9)	1 (1.4)
3. Changes in sexual interest since diagnosed with cancer	19 (27.1)	50 (71.4)	1 (1.4)
4. Changes in partners interest in sexual relationship since diagnosis *	14 (20.0)	47 (67.1)	2 (3.2)

*Only applies to participants with a partner; the percentage is calculated from n=63. ** Only applies to participants who have been sexually active within the last month; the percentage is calculated from n=53.

(p=0.0002). Twenty-nine (54.7%) of the men had experienced some degree of erectile dysfunction during the past month. The most commonly reported risk factors for sexual dysfunction among the male participants were hypertension (45.3%) and overweight (30.2%) (Table 4), but no significant association was observed.

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Table 4. Sexually active men (n=53) and risk factors for male sexual dysfunction

	Yes No (%)	No No (%)	Unknown No (%)	Association with sexual problems before operation	Association with sexual problems after operation	Association with erection problems
Diabetes	4 (7.5)	48 (90.6)	1 (1.9)	0.71	0.47	1.00
Hypertension	24 (45.3)	27 (50.9)	2 (3.8)	0.72	0.46	0.84
Alcohol	8 (15.1)	33 (62.3)	12 (22.6)	0.51	0.10	0.89
Smoking	8 (15.1)	38 (71.7)	7 (13.2)	0.19	0.91	0.57
Overweight	16 (30.2)	17 (32.1)	19 (35.8)	0.24	0.37	0.79

"*I don't know if there are others, who experience what I do-that an erection becomes more difficult to achieve after operation*"

"*I had a little bit back then (erectile dysfunction), but that was nothing-it worked*"

"*For over one year my / desire was affected, together with the fear of not being able to perform, that really does affect the desire*"

"*The desire is present, it isn't missing, but to be honest it has gotten less after I became sick*"

"*That has gotten worse too (ejaculation), sometimes nothing happens*"

"*I don't have the same orgasm-something is wrong*"

Figure 1. Quotes from interviews

Interviews

All participants (143) were invited to take part in an interview. Thirty-three (9 women and 24 men) participants accepted the invitation, were contacted, and received information about the upcoming interview by e-mail, letter, or phone. However, 19 changed their minds and dropped out. Fourteen [2 women (mean age 35 years, range 43-27) and 12 men (mean age 65 years, range 44-84)] were interviewed; 5 (1 woman and 4 men) by phone and 9 (1 woman, 8 men) in person. Two themes were discussed in the semi-structured interviews: "changes in sex life" and "information."

Changes in sex life

Six of the men claimed they experienced new or worsened erectile problems after their surgery. *"I still want to do it, but it just can't be done. It is very frustrating for my wife that I start something and then nothing happens"* (Figure 1). However, desire was negatively affected in 4 of the men and 1 of the women. One connected the loss of desire to the development of erectile dysfunction. Others stated that the entire situation affected their desire. "*I don't have the same desire anymore; there are other things to take into consideration."* Six of the men complained about ejaculatory dysfunction*: "I have the feeling (orgasm), but it won't come out."*

Many of the interviewees also mentioned the importance and impact of these sexual changes on their marriage/relationship. They emphasized frustration and loss of intimacy, and their concern for their partner.

"Well, it is very frustrating, it really is, because sex is an important part of a marriage, so it is an essential thing that I am missing, and the same goes for my wife. But she is very indulgent, and she says she doesn't mind that much. But sometimes I can tell that she wants to have sex."

At the same time, a feeling of togetherness and partnership was also described; *"I don't think that I have experienced any (sexual) problems, but then again, I have a wife who completely supports me"* (Figure 1).

Information

Only very few of the interviewees had been given any information about potential sexual complications. When asked, all except one would have liked some information. *"If they had a suspicion that it (operation) could affect my sex life, then I would have liked to know."*

Different options were discussed in relation to information. Some of the interviewees would have liked to receive information as a part of the information they received before their operation, and others after their operation. A few interviewees preferred a brochure or information movie. All except one would have liked to be informed *"Yes, I think so, because I*

would like to act on it, to be prepared, and to nip it in the bud" (Figure 1).

Discussion

This study shows that patients undergoing nephrectomy or nephro-ureterectomy experience several post-surgery sexual problems. More than half (61%) reported being worried about their sex life. Negative changes in sex interest since diagnosis were reported by 19 (27%) patients, and negative changes in their partner's sex interest was reported by 14 (20%). Only few participants (5%) had been informed about these potential problems perioperatively. Hence, most of the participants were uninformed about these potential problems. This was also revealed in the interviews in which none of the participants stated that they had received such information.

The present study, to the best of our knowledge, is one of the first studies investigating the sex life of patients with kidney cancer after surgery. Using questionnaire and interviews, we found that patients experienced sexual dysfunction to a larger extent after surgery than before surgery. Furthermore, we found that both the patients' and their partners' sexual desire was affected, which supports previous findings.[9,12] A study from 2003,[13] investigating the sex life of kidney cancer patients after treatment (operation, radiation or chemotherapy) found that most of the participants continued to be in relatively well-adjusted relationships. However, the study also suggested the presence more severe sexual function impairments in patients with kidney cancer than in other cancer patients. Furthermore, both men and women stated that their current sex life was less pleasurable than before cancer treatment. However, a comparison of the two studies is not straightforward for several reasons: first, different questionnaires were used. Second, comparison of the studies was hampered by the fact that the study from 2003 did not include interviews. Even so, both studies conclude that the sex life of patients with kidney cancer is harmed by treatment.[13]

It is difficult to explain what causes the sexual dysfunction, because it is not the surgical approach, but it could be being upset for having cancer, life stress, and losses. However, it is well know that getting the diagnosis of cancer affects the sex life. Research in this field is sparse, so it was hardly surprising that most participants were not informed about the potential sexual complications following surgery. However, previous research has shown that cancer patients experience changes in their sex life,[7-9] and furthermore these patients are interested in and need information on how to deal with these changes. Our findings are in compliance, and unfortunately, information is not provided to this group of patients.[7-9,14,15] This was also confirmed by the in-depth interviews in our study, which revealed that only 7 (5%) patients were informed about potential negative effects of surgery. Hence, our findings support that changes in sex life are rarely addressed in clinical settings.

Another aspect that underlines the need for proper information is the fact that 61.4% of patients in the present study reported that they were worried about their sex life, and every interviewed expect 1 would have liked to be informed about this. Horden conducted interviews with cancers patients,[14] and a large number expressed that they were worried about their sex life and if the changes they were experiencing in regard to their sex life were normal. More information and sexual counselling could potentially improve sexual function,[16,17] and therefore hopefully reduce concerns and worry among patients and their partners.

Problems with achieving an erection were reported by 29 (55%) of the men, and by 6 out of the 12 interviewees. In the questionnaire, no significant association was found between problems with achieving an erection and known risk factors for erectile dysfunction such as being overweight, smoking,[18] diabetes, and hypertension.[19] Thus, the erectile problem was probably a result of the operation.

There is a number of strengths and limitations of the present study that must be acknowledged. The main strength is an overall high response rate (68.1%), despite the sensitive nature of the topic and the combination of a questionnaire survey and interviews. This dual approach highlights different aspects of the topic and allows for a better and more varied insight than if a single source of data had been used. We chose to conduct individual interviews rather than focus group interviews because of the sensitive nature of the topic and because we believed that this approach would allow the participants to feel more comfortable and give us more honest in-depth answers.

A limitation to this study is, that a part of the study has a retrospective design, as well as the small patient population included in the study. To maintain power, we did not exclude the few participants who failed to fill out the entire questionnaire. Hence, some data were missing, which introduces a risk of bias. Furthermore, due to the small sample size, it was not possible to compare the different operation methods (nephrectomy vs. nephro-ureterectomy). It would have been interesting to explore if any difference in frequency of sexual problems could be associated with the surgical techniques. One would expect the frequency of sexual dysfunction to be higher in the nephro-ureterectomy group, considering that this operation involves a risk of damaging the nerves in the pelvic region.

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Furthermore, the male preponderance among respondents in the questionnaire and the interviews meant that women were underrepresented. Even if men and women were mostly comparable in terms of demographic data, this skewness remains a possible confounder.

We used a cross-sectional design combined with interviews, but all the assessments were retrospective. A prospective design following patients over time from before their diagnosis or surgery to the period after surgery would allow for a more accurate and more effective evaluation of the changes in patients' sexual function. For some of the participants, being interviewed on average more than 2 years after having undergone surgery might introduce the recall bias. Finally, an increasing age is correlated with an increased frequency of erectile dysfunction, which was a common complaint in our study group. Changes in sex life after cancer might persist for years,[9] so the results ought to be representative for this patient group.

We did not assess the cognitive function of the patients participating in the study. We identified patients retrospectively and were therefor not able to evaluate cognitive changes due to surgery. In addition, we did not use a validated questionnaire, e.g., International Index of Erectile Function (IIEF-5), to assess the erectile function because it was not used preoperatively. The patients were asked to compare and evaluate their sexual function in their own words. Using a validated questionnaire would have heightened the data; however, the main purpose of this study was fulfilled. We aimed to elucidate the need for bringing more attention to the negative effects of nephrectomy on sexual function.

In conclusion, this present study indicates that patients undergoing kidney cancer surgery experience more problems with sexual relationships after the operation and that there is an unmet need of informing such patients perioperatively.

It might be worth considering informing future patients about these potential problems with sexual relationships and maybe offer sex counselling to hopefully reduce these problems. More studies are needed in the future to fully elucidate the extent of this problem.

Ethics Committee Approval: This is a quality-based study and therefore it does not require an approval from the local scientific ethical committee according to Danish legislation.

Informed Consent: Participation in interviews and questionnaires was optional, and a positive reply from the patient was considered tantamount to informed consent.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept - R.P., L.L.; Design - R.P., A.H., L.L.; Supervision - L.L.; Data Collection and/or Processing - R.P., N.A., L.L.; Analysis and/or Interpretation - R.P., N.A., L.L.; Literature Search - R.P., A.H., L.L.; Writing Manuscript - R.P.; Critical Review - A.H., L.L.

Conflict of Interest: The authors have no conflicts of interest to declare.

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