



Universiteit
Leiden
The Netherlands

Reproductive and sexual health care in oncology: current practice and challenges

Krouwel, E.M.

Citation

Krouwel, E. M. (2022, May 12). *Reproductive and sexual health care in oncology: current practice and challenges*. Retrieved from <https://hdl.handle.net/1887/3303552>

Version: Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden](#)

Downloaded from: <https://hdl.handle.net/1887/3303552>

Note: To cite this publication please use the final published version (if applicable).



Chapter 3

Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists

E.M. Krouwel, J.H. Hagen, M.P.J. Nicolai, A.L. Vahrmeijer, H. Putter,
R.C.M. Pelger, H.W. Elzevier

Eur J Surg Oncol. 2015 Sep;41(9):1179-87.

INTRODUCTION

Cancer patients commonly experience sexual problems, regardless of cancer origin or age of onset.^{1,2} The occurrence and degree of sexual dysfunctions are subject to the localization of the disease and the sort of treatment. Surgery is known to be of considerable influence for sexual functioning and is frequently part of a cancer treatment. The primary aims of surgical cancer treatment are cure and survival, however, consequences such as poor bowel and bladder function, a (temporary) stoma, physical weakness, pain, scars, nutrition related problems and body image issues are serious and in many cases influence the sexual functioning. The adverse impact of surgical treatment to sexual function is an underestimated problem and may arise as a result of physical, psychological and social changes. Sexual health encompasses functioning across these particular domains and is hence defined as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.”³ Many circumstances may cause sexual issues in cancer patients, such as general physical debility, somatization, change in lubrication, erectile dysfunction, ejaculation disorder, depression, anxiety and decreased desire.⁴ Changes may result from direct effects of the surgery on physical function (e.g. nerve damage), due to indirect effects of the surgery on psychological function (e.g. mastectomy or stoma impacting body image and desire) and some changes may be due to broader effects of cancer and its treatment across any of the domains (e.g. fatigue, loss of libido, illness, social stress and loss of sexual partner). Sexual dysfunction has a great impact on the quality of life of cancer patients, and with improving prognosis attention for sexual health is being acknowledged as an important excellence indicator of comprehensive care.^{1,4,5} Gradually, as oncology treatment objectives are extending towards improved quality of life, evidence has increased on the treatment-related sexual burden and the corresponding need for information.

Previous surveys have documented sexual side effects are associated with a range of cancers. For example, in an Australian survey, 85% of 1965 patients with breast cancer reported changes to sexual well-being, with 68% wanting information on such changes.⁶ Only 16.6% of these participants had spoken about sexual well-being with their surgeon, of which only 43% was satisfied with this consultation. Mastectomy with or without reconstruction both have a significant impact on body image and sexual function in comparison to women who had a lumpectomy.⁷ Three years after mastectomy, feelings of sexual attractiveness and comfort during sexual activity are significantly decreased, as well as the feeling exists that the partner's sexual interest has decreased.⁸ One-third of patients who have undergone major head and neck carcinoma treatment reported substantial problems with sexual interest and intimacy.⁹ Colorectal surgery also often results in sexual dysfunction; approximately half of the women reported sexual dysfunction and the percentage of dysfunction in preoperatively potent men varied from 5% to 88%.¹⁰ Predictors for sexual dysfunction following colorectal surgery include preoperative radiotherapy, a stoma, complications during or after surgery and a higher age.¹⁰ After rectal surgery, specific sexual issues in women are libido 41%, arousal 29%, lubrication 56%, orgasm 35%, and dyspareunia 46%,

and in men libido 47%, impotence 32%, partial impotence 52%, orgasm 41%, and ejaculation 43%.¹¹ Men with a colostomy reported erectile dysfunction in 79% of the cases, though a (temporary) colostomy affects sexual function in many ways.¹² Patients with rectal cancer who have undergone surgery, considered sexual function an important overall outcome. However, only 9% of women and 39% of men remembered talking about the sexual side-effects of surgery preoperatively.¹¹ Among patients with gynaecologic, breast or colorectal cancer, 37% received information about how surgery possibly affects their body image and sexual well-being.¹³

When it comes to bringing up the subject during a consultation with a physician, patients experience several barriers.^{14,15} Nonetheless, the great impact of sexual dysfunction on quality of life indicates it is important for health care providers to inform patients on sexual side effects and detect if a patient is experiencing any problems.¹⁶ Knowing that most patients will not initiate a conversation about sexuality, health care providers carry the responsibility to address this issue.¹ Well-informed patients have an advantage in coping with consequences of surgery as complications are better tolerated if they are anticipated.¹⁷

So far, in the last decades research mainly focused on counselling of sexual concerns by oncology nurses. In the position of having frequent contact with patients and providing medical and emotional support, oncology nurses play a significant role in detecting and discussing personal issues, including sexual concerns. However, physicians are the patients' primary responsible medical attendant and source of information concerning treatment and side effects. To our knowledge, extensive information concerning the presumed role of the surgeon in sexual counselling is not available yet. Aim of this study was to evaluate current practice, attitude and opinions of Dutch surgical oncologists towards information provision and communication about sexual issues. By identifying barriers, ideas about responsibilities and the potential need for additional training; recommendations can be made for improvement of sexual health care for surgical cancer patients.

MATERIALS AND METHODS

Study design

A cross-sectional survey was performed among surgical oncologists practicing in the Netherlands. All surgeons and surgical residents registered as a member of the Dutch Society for Surgical Oncologists (NVCO) received a questionnaire by postal mail in August 2013 (n = 437). An information letter and a post-paid return envelope were added. A reminder was sent after 6 weeks, a second reminder 13 weeks after the initial mailing. All data were collected anonymously.

Questionnaire design

The questionnaire was developed by the authors and has been shown to be applicable in several studies conducted by our research group.¹⁸⁻²¹ The questionnaire comprised 31 items, assessing sociodemographic factors (i.e. age, sex, function, type of practice, areas of expertise, and time of practice) and 5-point Likert-scale items investigated the following topics: - Frequency of

discussing sexual issues - Responsibility for dealing with sexual issues - Knowledge about sexual issues related to surgery - Training needs of surgical oncologists - Barriers in discussing sexual issues. First a pilot study was performed among 11 surgical oncologists employed in the Leiden area, in order to evaluate the face and content validity of the questions. Based on their comments the instrument was adjusted.

Statistical analysis

Data were analysed using SPSS release 20 (SPSS Inc., Chicago, IL, USA). Frequency distribution was used to describe the data. Bivariate associations between demographic information and specific answers were made with Pearson's chi-square test, for ordinal variables the Armitage's trend test was used. For paired answers, the McNemar test was used. Continuous variables were compared using the Student's t-test. Correlations between paired items and questions containing multiple possible answers were computed with the Wilcoxon signed rank test. P-values <0.05 were considered statistically significant.

Ethical considerations

In the Netherlands, research that does not involve patients or interventions, is not subject to approval from ethical boards. In previous research where nurses were the participants, the Medical Ethics Committee was consulted. As the study did not concern any information recorded by the investigator in such a manner that subjects could be identified, and as it did not compromise the study participants' integrity, the Committee declared that no formal ethical approval was needed.²⁰

RESULTS

The survey was distributed among 437 surgical oncologists, 190 of them were returned. From 24 surgeons a notification of refusal was received, 6 surgeons stated refusal due to lack of time, 4 due to lack of interest, 4 stated that oncology was not their area of expertise and 3 indicated they only worked with children. Other reasons mentioned were lack of experience (n ¼ 2), retirement (n ¼ 2), residency or employment outside the Netherlands (n ¼ 2) and 'improvement in this area is not necessary' (n ¼ 1). One questionnaire was eliminated because it was incomplete (>20% missing data). A total of 165 questionnaires were included for analysis, resulting in a response rate of 37.7%.

Demographics

Of the respondents 87.8% were surgical oncologists, 6.1% were general surgeons and 6.1% were residents. The majority of the surgeons were men (73.6%). The mean age of male respondents was 48.2 years (SD 9.3) and for female respondents 41.1 years (SD 5.7), a significant

difference ($p = 0.002$). Most common areas of expertise were colorectal and breast surgery, both mentioned by 67.9% of the respondents. Demographic data are summarized in Table 1.

Table 1. Respondents characteristics (n=165)

		<i>n (%)</i>
Age (years)	Median 45 years (range 31-66)	163 (98.8)
	Mean 46.4 years (SD 9.0)	
	NA	2 (0.2)
Gender	Male	120 (72.7)
	Female	43 (26.1)
	NA	2 (1.2)
Function	Surgical oncologist	145 (87.8)
	General surgeon	10 (6.1)
	Resident	10 (6.1)
Type of practice	University hospital	35 (21.2)
	District general teaching hospital	71 (43.0)
	District general hospital	46 (27.9)
	Cancer institute	9 (5.5)
	NA	4 (2.4)
Time of practice	0-11 months	3 (1.8)
	1-2 years	18 (10.9)
	3-5 years	35 (21.2)
	6-10 years	32 (19.4)
	11-15 years	21 (12.7)
	15 years or more	56 (33.9)
Area of expertise ^a	Breast	112 (67.9)
	Colorectal	112 (67.9)
	Rectal	70 (42.2)
	Melanoma	70 (42.2)
	Skin	40 (24.2)
	Head and neck	34 (20.6)
	Stomach	33 (20.0)
	Liver	31 (18.8)
	Sarcoma	26 (15.8)
	Oesophagus	24 (14.5)
	Pancreas	16 (9.7)
	Lung	16 (9.7)
	Neuro-endocrine	13 (7.9)

NA: Not available.

a) Most respondents reported multiple areas of expertise.

Sexual counselling

Table 2 presents respondents' self-reported daily practice on counselling for sexual issues. To the question "how often do you discuss sexual health with your patients?" 36.6% of the surgeons answered 'never/rarely', 44.5% said 'in less than half of the cases'. Regarding the question "how often do you provide informed-consent about the possible effects on sexual functioning?" 53.6% answered in less than half of the cases, 46.4% said in half of the cases or more. Informed consent regarding specific procedures is presented in Table 3. Male respondents discussed sexual function significantly more often (linear-by-linear association, $p = 0.045$). Furthermore, surgeons aged 46 years or above stated to discuss sexual issues more regularly than younger respondents (linear-by-linear association, $p = 0.006$). Experienced surgeons (≥ 6 years of practice) started conversation about sexual problems more often than less experienced surgeons, this difference was not significant ($p = 0.085$). During an informed consent conversation, male surgeons (51.3%) discussed effects on sexual function more frequently in comparison to female colleagues (30.2%) with half or more of the patients (linear-by-linear association, $p = 0.016$).

The respondents discussed sexual health with an average estimation of 23.1% (SE 1.94, range 0-100%) of their patients. According to the surgeons, referral to other health care providers for treatment of sexual problems occurs in an estimated 5.83% (SE 0.63, range 0-50%). Sexual issues were more often discussed with male patients (Wilcoxon rank test $p < 0.001$).

Table 2. Questions concerning the handling of sexual issues.

	Never/ rarely	In less than half of the cases	In half of the cases	In more than half of the cases	Often/ always
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
How often do you discuss sexual health with your patients?	60 (36.6%)	73 (44.5%)	16 (9.8%)	8 (4.9%)	7 (4.3%)
How often do you inform your patients about the possible effects on sexual health during an informed-consent conversation?	44 (26.8%)	44 (26.8%)	16 (9.8%)	22 (13.4%)	38 (23.2%)
During the first visit, how often do you discuss sexual health with patients?	44 (31.0%)	60 (42.3%)	11 (7.7%)	14 (9.9%)	13 (9.2%)
During follow-up, how often do you discuss sexual health with patients?	46 (32.4%)	54 (38.0%)	21 (14.8%)	6 (4.2%)	15 (10.6%)
How often do patients bring up sexual complaints of one's own accord?	67 (45.9%)	61 (41.8%)	10 (6.8%)	5 (3.4%)	3 (2.1%)
When discussing sexual health, how often is the patient's partner present?	9 (6.2%)	27 (18.6%)	25 (17.2%)	49 (33.8%)	35 (24.1%)
How often do you prescribe phosphodiesterase-5 inhibitors for patients with erectile dysfunction?	126 (89.4%)	9 (6.4%)	2 (1.4%)	4 (2.8%)	0 (0.0%)

Table 3. Provision of informed consent.

How often do you provide information regarding sexuality to patients who...	Never	Rarely	Regularly	Often	Always	Not applicable ^a
	<i>n (%)</i>					
	<i>n (%)</i>	<i>n (%)</i>		<i>n (%)</i>	<i>n (%)</i>	<i>n</i>
Will undergo breast surgery	21 (18.4)	54 (47.4)	22 (19.3)	11 (9.6)	6 (5.3)	30
Will (possibly) receive a stoma	15 (11.6)	49 (38.0)	37 (28.7)	20 (15.5)	8 (6.2)	15
Will undergo rectal surgery with possible nerve damage	2 (1.6)	3 (2.4)	20 (16.1)	28 (22.6)	71 (57.3)	20
Will undergo a serious mutilating procedure	16 (13.3)	51 (42.5)	22 (18.3)	23 (19.2)	8 (6.7)	23
Will undergo a colectomy because of a premalignant condition	16 (16.0)	23 (23.0)	15 (15.0)	22 (22.0)	24 (24.0)	44

Question was only answered if applicable to the surgeons area of expertise.

Responsibility

Of the respondents, 75.9% agreed to the statement ‘surgical oncologists have the responsibility to discuss sexual health with their patients’, 11.1% did not know who is responsible and 13.0% thought it to be somebody else’s responsibility ($n = 162$). To the question ‘Who is responsible for addressing sexual function’ 85.5% pointed at the surgical oncologist to be responsible itself. Responsibility appointed to all oncology team members and the patient or partner is displayed in Fig. 1.

Of the respondents with breast surgery as their area of expertise, 69.4% agreed with the statement of surgical oncologists holding responsibility for discussing sexual issues, of the respondents without breast surgery as their area of expertise 90.2% agreed (linear-by-linear association, $p = 0.016$). Of the respondents with and without colorectal surgery as area of expertise respectively 85.4% and 55.8% agreed with this statement, also a significant difference (linear-by-linear, $p < 0.001$).

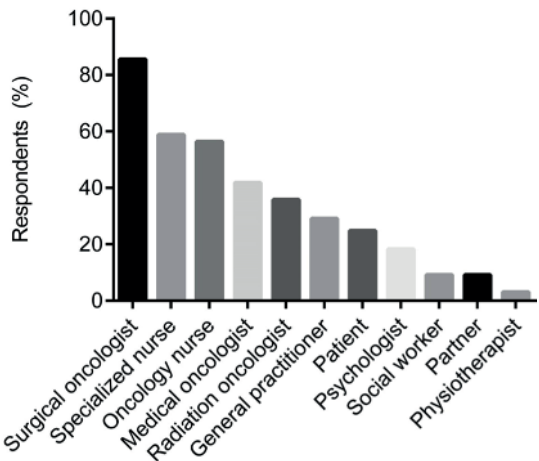


Fig 1. Answer to the question: ‘Who is responsible for addressing sexual function according to respondents?’ (multiple answers possible).

Knowledge and training needs

Respondents ($n = 163$) estimated that on average 56.7% (SE 1.89) of their patients experience changes in their sexual life. Written patient information about sexual problems is available in the clinic of 50% of the surgeons ($n = 144$). Of the responding physicians, 20.6% indicated to possess sufficient knowledge on sexual dysfunctions and its treatment, other respondents stated to have some (49.3%) or little (30.2%) knowledge ($n = 146$). Surgeons with more self-stated knowledge discussed sexual issues more often (linear-by-linear, $p < 0.001$). When it comes to training needs, 46.3% ($n = 74$) would like to acquire more training on the counselling of sexual (dys)function. According to 79.6% ($n = 129$) current training during surgical residency is not sufficient with regard to the counselling of sexual function.

Barriers

Respondents were asked to what extent they agreed with a list of possible barriers for discussing sexual function, these were listed in Table 4. Surgeons with short experience (5 years) significantly more often agreed with the barriers 'lack of training' and 'lack of knowledge' (linear-by-linear, $p = 0.030$ and $p = 0.003$, respectively), as well as respondents who would like to acquire more knowledge about the subject of sexual health and respondents who indicated the current training was not sufficient (linear-by-linear, $p < 0.001$).

Table 4. Barriers.

Reasons for avoiding discussion of sexual health	Agree ^a	Partly agree/ partly disagree	Disagree ^a
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Advanced age of the patient	81 (50.6)	41 (25.6)	38 (23.8)
Not relevant for all type of cancers	71 (43.8)	28 (17.3)	63 (38.9)
Lack of time	65 (39.9)	41 (25.2)	57 (34.9)
No angle or motive for asking	57 (35.2)	44 (27.2)	61 (37.6)
Lack of training	54 (32.9)	39 (23.8)	71 (43.3)
Patient doesn't bring up the subject	52 (32.1)	34 (21.0)	76 (46.9)
Language/ethnicity	49 (30.6)	42 (26.3)	69 (43.1)
Presence of a third party	42 (25.9)	41 (25.3)	79 (48.8)
Culture/religion	41 (25.1)	52 (31.9)	70 (43.0)
Surviving is more important	39 (24.1)	52 (32.1)	71 (43.8)
Lack of knowledge	39 (23.8)	55 (33.5)	70 (42.7)
Patient is not ready for discussing sexual issues	32 (19.5)	54 (32.9)	78 (47.6)
Patient is too ill	28 (17.2)	57 (35.0)	78 (47.8)
Sexuality is not a matter of life and dead	23 (14.3)	50 (31.1)	88 (54.6)
I feel uncomfortable	23 (14.2)	46 (28.4)	93 (57.4)
Sexuality is not a patient's concern	20 (12.4)	52 (32.3)	89 (55.3)
Patient doesn't want to discuss the subject with me	19 (12.1)	57 (36.3)	81 (51.6)

Table 4. Barriers. (continued)

Reasons for avoiding discussion of sexual health	Agree ^a	Partly agree/ partly disagree	Disagree ^a
It's other ones task	18 (11.2)	41 (25.4)	102 (63.4)
Concerned to raise discomfort to the patient	18 (11.0)	44 (27.0)	101 (62.0)
Sexuality is a private matter	15 (9.2)	43 (26.4)	105 (64.4)
Embarrassment	12 (7.4)	25 (15.4)	125 (77.2)
Age difference between you and patient	12 (7.4)	22 (13.6)	128 (79.0)
Patient doesn't have a partner	11 (6.8)	45 (28.0)	105 (65.2)
Afraid to offend the patient	10 (6.2)	20 (12.3)	132 (81.5)
No trust in treatment for sexual dysfunction	6 (3.7)	37 (23.0)	118 (73.3)
Patient is the opposite gender	5 (3.1)	10 (6.2)	147 (90.7)
Colleagues think it's inappropriate to discuss sexual issues with patients	1 (0.6)	6 (3.8)	153 (95.6)
Patient is the same gender	0 (0)	6 (3.7)	156 (96.3)

a) For ease of presentation, results in response categories 'Strongly agree' and 'agree' have been merged, as have 'strongly disagree' and 'disagree'.

DISCUSSION

The present study provides insight into the practice patterns of Dutch surgical oncologists in the discussion of sexual function. Key findings are that surgical oncologists do not routinely discuss sexual issues and in the majority of cases do not inform their patients about sexual side effects of surgery. According to the surgeons current practice is attributable to multiple reasons, including advanced age of patients, not relevant for all types of cancers and a lack of time. The extent and comfort with discussion of sexual issues increases with years of practice. Gender and age characteristics also influence practice; male surgeons address the subject more often as well as surgeons aged 46 years and above. The majority of surgeons stated current surgical training to be insufficient on sexual education, almost half of the responding surgeons wished to acquire more knowledge on this topic. A very small percentage of patients is referred for sexual problems.

This survey was one of the first to evaluate the attitudes and behaviour of surgical oncologists towards discussing sexual health. With exception of a Japanese survey amongst breast surgeons performed in 2001, little is known about whether surgical oncologists discuss sexuality with their patients.²² Whereas The Global Survey of Sexual Attitudes and Behaviours revealed that women in East Asia were the least likely to talk to a doctor about their sexual issues (9% v 18%-40% in non-Asian country groups), the Japanese survey results might differ significantly from a non-Asian perspective.²³ Similar studies examining the behaviour of gynaecologic oncologists towards discussing sexual health found percentages of 7% and 49% regarding the discussion of sexual health with half or more of the patients.^{24,25} Barriers found to the provision of sexual counselling were lack of time, limited experience and inadequate knowledge, in concordance

with our results.^{24,25} Previously found barriers for health care providers in addressing sexual issues with colorectal patients were lack of knowledge and competence, not feeling responsible and gender and age of the patient.¹⁵ Lack of experience, knowledge and competence are evidently recurrent barriers, indicating there is a major role for education and practical training in improving frequency of practice.

An interesting finding of the present study is that more than fifty percent of the surgeons stated 'advanced age of the patient' as an argument for avoiding the discussion on sexual dysfunction. A majority of the responding surgeons seemed to believe that elderly patients are not sexually active anymore and for this reason the subject is not relevant for them. This assumption might be incorrect in a fair bit of patients; according to a study on the prevalence of sexual activity among 3005 adults 57-85 years of age a significant percentage of older adults is still sexually active.²⁶ The percentage of adults being sexually active was 73% among who were 57-64 years of age, 53% among adults who were 65-74 years of age, and 26% of the persons who were 75-85 years of age. Another barrier many surgeons agreed with was 'not relevant for all type of cancers'. This finding is disappointing because sexual problems potentially occur in all cancer patients, regardless of cancer type.² With reference to changes in sexual health across cancer types, it is striking how in comparison to surgeons with other specializations breast surgeons feel less responsible for discussing sexual problems. Despite diminished sensibility in the areola, it is also crucial to discuss body-image and reconstruction in concordance with the plastic surgeon. Fortunately, among colorectal surgeons appears to be a greater awareness of sexual dysfunction following surgery.

A significant part of the surgeons indicated that lack of time is another common reason for avoiding the discussion of sexual health. With an average ten minute surgical consultation in which a cancer diagnosis, treatment plan, pathology results, postoperative consequences or recurrence of disease have to be discussed, one can imagine that time constraints are a barrier according to the surgeons' point of view. This finding corresponds to a survey among oncologists; one of the major barriers was that they often have a limited amount of time to go into detail of the diagnosis and the treatment plan, as a result limited time remains for the psychosocial concerns.²⁷ Extensive discussion of the subject might take a lot of time, nevertheless, simply assigning to the topic and providing a patient the opportunity to discuss concerns and ask for referral would be a major improvement of current practice.

The common occurrence of sexual problems after numerous types of surgery, suggests that it would be beneficial to routinely ask patients about this and refer them for guidance if needed. However, sexual issues are difficult to raise and discuss during a regular consultation. Even though increasing evidence emphasizes the relevance of discussing sexual concerns with patients, surgeons and other health professionals have had little or no training in discussing sexual issues and rarely raise this topic.²⁴ On the contrary, cancer patients are willing to discuss sexuality and reported to be dissatisfied with the time spent discussing it.²⁸ Therefore, together with the medical oncologists, radiation oncologists, plastic reconstructive surgeons, oncology

nurses and if applicable the general practitioner, the surgical oncologist has the responsibility of dealing with possible sexual concerns of their patients. Interdisciplinary care is presumed to be the best care, with disciplines working within their roles in an integrated fashion to address the patient's whole health including sexual health.

As for the surgeon, providing thorough informed consent is a legal obligation in advance of a procedure. In case of rectal-, anal-, breast or any other form of nerve and body image damaging surgery, information regarding sexual deterioration should be part of the informed consent like other secondary effects. With respect to the surgical practice, it is well known that potential direct effects to sexual functioning are often both in advance as well as postoperatively a patient's concern. On account of the patient's need for information on sexual side-effects, the surgeon should integrate the provision of this information into the collective clinic in some way. Not all patients need major discussion of their sexual health. The authors do, however, believe that as a part of informed consent for surgery, potential direct sexual side effects should be disclosed. Furthermore, if the subject is addressed once postoperatively, the patient can then decide to bring it up again if important. The postoperative counselling does not necessarily need to be done by the surgeon; in each surgical department oncology nurses, social workers or psychologists who feel confident with discussing sexual health could evaluate with patients whether questions have arisen. As for the nurses, social workers or psychologists who completed additional training on sexual counselling, efforts can be made to not only address the direct effects of surgery but also other indirectly derived sexual issues. In addition, considerable benefit could be derived by implementing a clinical nurse specialist on quality of life and sexuality, as investigated for gynaecological oncology purposes with noteworthy results.²⁹ Finally, a list with specialized sexual health care providers in the surgical practice might be greatly beneficial for referral of patients in need of specialized counselling. On behalf of integrity in daily practice, a couple of practical recommendations are presented for sexual counselling by surgeons:

I. Experts in the field recommend several effective ways to broach the topic of sexuality during a consultation. For example, opening the discussion with a normalizing statement such as "It is part of my routine to ask about sexual health as part of the regular consultation. Do you have any concerns?". Or you might question the patient saying "Some studies show that as someone has cancer, they may have less desire for sex or decreased lubrication/erection, which makes intercourse uncomfortable/ impossible. Have you noticed any changes?".³⁰ Another angle for raising the subject is for instance "It is known that many people, despite the presence of severe illness, or even due to severe illness, have a need for intimacy. It is also known that due to all the changes, disease and treatment, problems and insecurity could occur in this area. How's that for you?".³¹ With regard to informed consent disclosure, the surgeon might use a sentence like "One side effect of this surgery is that the surgery could affect your sexual health. I am operating on body part x that could affect your sexual functioning like y. Of course, sexual health is a complicated matter with physical, emotional and social elements. What you should know before the surgery is the specific physical risks, and also that your health care team can

work with you after your treatment to address ongoing concerns you might have about your sexual health.”

II. II. The PLISSIT model was designed to assist health care providers with interventions on issues of sexuality, and is widely used and adopted by organizations concerning diverse professions.³² The model is suitable to surgeons who would like to integrate sexual counselling in their practice through a structured framework. The acronym PLISSIT represents four levels of an intervention: Permission (P), limited information (LI), specific suggestion (SS) and intensive therapy (IT). Physicians are not expected to be skilled in order to function at all four levels, as only few patients require intensive therapy to resolve their sexual dysfunction. If applied, most patients will only enter the first Permission level of the model with the surgeon allowing the patient to discuss matters that would otherwise be too embarrassing. Where necessary, patients should be referred to others who are more able to address individual needs. In doing so, surgeons only have to work within the limits of their own comfort zone and competence.

The results of the present study may improve awareness of surgeons and encourage surgeons to inform patients prior to surgery, detect post-surgical issues and refer patients to sexologists for further counselling of their problems. Results also may encourage attending additional training for those who feel commitment, initiatives for local but also national guidelines and including this topic in the residency of future surgeons. Prospective, surgeons could actually have a key role in educating about sexual side effects; within their departments, towards medical students, surgical residents and most certain in educating patients, where partners should not be forgotten. Further research is required to investigate (1) the patient's opinion on adequate timing for counselling of sexual function during oncologic treatment and the desirable type of information offered (e.g. by personal contact, written information, e-health), (2) the role of the general practitioner with regards to late follow up, (3) the necessity of involving the sexual and romantic partner in counselling and most crucial (4) how to implement solutions beneficial to the unmet need for information on a large scale.

Study limitations

This study is limited since a self-reported questionnaire was used, this may have led to under- or overestimation. Questionnaire based studies are always subjected to response and selection bias. The survey was made anonymous to reduce this bias. Our response rate was considerably low compared to other postal questionnaires, hence a sampling error might have occurred.³³ However, a high response rate will not necessarily result in a more illustrative sample and methods of boosting response rates may introduce further bias.³⁴ In fact, the low response rate may be interpreted as a reflection of one of the main barriers: lack of time.

Implications for practice

In spite of the available research on sexual problems occurring due to surgical treatment of cancer, sexual health is often not a part of consultation by surgical oncologists in the Netherlands. Although sexual issues are broadly recognized and established in oncology care; its implementation in cancer surgery has not yet been completed. This study suggests that knowledge, experience and training play an essential role in discussing sexual health with patients, emphasizing the need for additional tutoring. To optimize healthcare and to optimally assist patients in their recovery and return to health, involved oncology health care providers should agree on who is responsible for discussing sexual health, at which moment this discussion should take place and to which extent it should be discussed. The sexual health care for surgical oncology patients can be improved with the use of protocols on responsibility, the provision of patient information and optimization of referral in regard to sexual issues.

REFERENCES

1. Bolte S, Zebrack B. Sexual issues in special populations: adolescents and young adults. *Semin Oncol Nurs* 2008;24(2):115–9.
2. Mercadante S, Vitrano V, Catania V. Sexual issues in early and late stage cancer: a review. *Support Care Cancer* 2010;18(6):659–65.
3. World Health Organization. Defining sexual health: report of a technical consultation on sexual health, 28e31 January 2002 2006. Geneva.
4. Andersen BL. Sexual functioning morbidity among cancer survivors. Current status and future research directions. *Cancer* 1985;55(8): 1835–42.
5. Lemieux L, Kaiser S, Pereira J, Meadows LM. Sexuality in palliative care: patient perspectives. *Palliat Med* 2004;18(7):630–7.
6. Ussher JM, Perz J, Gilbert E. Information needs associated with changes to sexual well-being after breast cancer. *J Adv Nurs* 2013;69(2):327–37.
7. Rosenberg SM, Tamimi RM, Gelber S, et al. Body image in recently diagnosed young women with early breast cancer. *Psychooncology* 2013;22(8):1849–55.
8. Fallbjork U, Rasmussen BH, Karlsson S, Salander P. Aspects of body image after mastectomy due to breast cancer e a two-year follow-up study. *Eur J Oncol Nurs* 2013;17(3):340–5.
9. Low C, Fullarton M, Parkinson E, et al. Issues of intimacy and sexual dysfunction following major head and neck cancer treatment. *Oral Oncol* 2009;45(10):898–903.
10. Traa MJ, De VJ, Roukema JA, Den Oudsten BL. Sexual (dys)function and the quality of sexual life in patients with colorectal cancer: a systematic review. *Ann Oncol* 2012;23(1):19–27.
11. Hendren SK, O'Connor BI, Liu M, et al. Prevalence of male and female sexual dysfunction is high following surgery for rectal cancer. *Ann Surg* 2005;242(2):212–23.
12. Krouse R, Grant M, Ferrell B, Dean G, Nelson R, Chu D. Quality of life outcomes in 599 cancer and non-cancer patients with colostomies. *J Surg Res* 2007;138(1):79–87.
13. Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. Information needs and experiences: an audit of UK cancer patients. *Eur J Oncol Nurs* 2006;10(4):263–72.
14. Hordern A, Street A. Issues of intimacy and sexuality in the face of cancer: the patient perspective. *Cancer Nurs* 2007;30(6):E11–8.
15. Traa MJ, De VJ, Roukema JA, Rutten HJ, Den Oudsten BL. The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals. *Support Care Cancer* 2014;22(3): 763–72.
16. McKee Jr AL, Schover LR. Sexuality rehabilitation. *Cancer* 2001; 92(4 Suppl.):1008–12.
17. Breukink SO, Donovan KA. Physical and psychological effects of treatment on sexual functioning in colorectal cancer survivors. *J Sex Med* 2013;10(Suppl. 1):74–83.
18. Nicolai MP, Both S, Liem SS, et al. Discussing sexual function in the cardiology practice. *Clin Res Cardiol* 2013;102(5):329–36.
19. Bekker M, Beck J, Putter H, et al. The place of female sexual dysfunction in the urological practice: results of a Dutch survey. *J Sex Med* 2009;6(11):2979–87.
20. Bekker MD, Van Driel MF, Pelger RC, Nijeholt GA, Elzevier HW. How do continence nurses address sexual function and a history of sexual abuse in daily practice? Results of a pilot study. *J Sex Med* 2011;8(2):367–75.
21. Krouwel EM, Nicolai MP, Steijn-van Tol AQMJ, et al. Addressing changed sexual functioning in cancer patients: a cross-sectional survey among Dutch oncology nurses. *Eur J Oncol Nurs*. [Epub ahead of print], available online 5 June 2015.

22. Takahashi M, Kai I, Hisata M, Higashi Y. Attitudes and practices of breast cancer consultations regarding sexual issues: a nationwide survey of Japanese surgeons. *J Clin Oncol* 2006;24(36):5763–8.
23. Moreira Jr ED, Brock G, Glasser DB, et al. Help-seeking behaviour for sexual problems: the global study of sexual attitudes and behaviors. *Int J Clin Pract* 2005;59(1):6–16.
24. Wiggins DL, Wood R, Granai CO, Dizon DS. Sex, intimacy, and the gynecologic oncologists: survey results of the New England Association of Gynecologic Oncologists (NEAGO). *J Psychosoc Oncol* 2007; 25(4):61–70.
25. Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer* 2003;88(5):666–71.
26. Lindau ST, Schumm LP, Laumann EO, Levinson W, O'Muircheartaigh CA, Waite LJ. A study of sexuality and health among older adults in the United States. *N Engl J Med* 2007;357(8): 762–74.
27. Adams E, Hill E, Watson E. Fertility preservation in cancer survivors: a national survey of oncologists' current knowledge, practice and attitudes. *Br J Cancer* 2013;108(8):1602–15.
28. Lindau ST, Gavriloa N, Anderson D. Sexual morbidity in very long term survivors of vaginal and cervical cancer: a comparison to national norms. *Gynecol Oncol* 2007;106(2):413–8.
29. Maughan K, Clarke C. The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. *J Clin Nurs* 2001;10(2):221–9.
30. Kingsberg SA. Taking a sexual history. *Obstet Gynecol Clin North Am* 2006;33(4):535–47.
31. Dutch Comprehensive Cancer Center. Oncoline guideline. Palliative care. Urogenital problems. Version 2.0 8-5-2010.
32. Annon JS. The PLISSIT model: a proposed conceptual scheme for the behavioral treatment of sexual problems. *J Sex Educ Ther* 1976;2(1):1–15.
33. Cummings SM, Savitz LA, Konrad TR. Reported response rates to mailed physician questionnaires. *Health Serv Res* 2001;35(6):1347–55.
34. Berry SH, Kanouse DE. Physician response to mailed survey: an experiment in timing of payment. *Public Opin Q* 1987;51(1): 102–14.

