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

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# Reproductive and sexual health care in oncology

*Current practice and challenges*



Esmée M. Krouwel



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Current practice and challenges  
Thesis, Leiden University

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# **Reproductive and sexual health care in oncology**

Current practice and challenges

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*Aan mijn ouders*  
*Voor Maurizio, Thibeaue en Mabel*



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# Chapter 1

*General introduction and thesis outline*



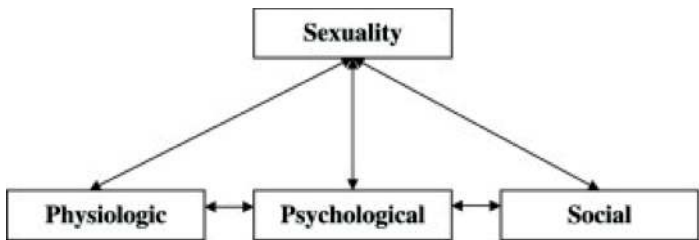
# GENERAL INTRODUCTION

## Cancer and sexuality

Being confronted with a cancer diagnosis of any kind is a life-changing event, with significant impact on well-being, quality of life and couple relationships (1). Cancer treatments and outcomes have dramatically improved in recent years but have the potential to impair endocrine, reproductive and sexual function (2-5).

### *Sexual function alterations*

Sexual functioning is a central aspect of human being, according to the World Health Organization, and involves several aspects like desire, activity, gender identity, sexual orientation, pleasure, intimacy and reproduction (6, 7). Also, for most cancer patients, sexual function is a proven, important aspect of quality of life, regardless of age and type of cancer (8-14). Among 41.2% of patients with one of the ten most commonly occurring cancers, sexual dysfunction is a concern approximately one year after being diagnosed (12). Cancer diagnosis and treatment regimens may have a severe impact on sexual function, both functional as well as emotional effects (15-17). Sexual side effects are wide-ranging and go beyond cancer treatment of solely the pelvic or breast organs (9, 18-20). Alterations in sexual function of cancer patients and survivors are complex, and several circumstances may lead to changes in physiologic, psychological and social dimensions of sexuality, as displayed in Figure 1 (21, 22). Not only direct effects may alter sexual function, also symptoms like fatigue, pain, incontinence, depression, but anxiety and disfigurement may interfere with patients' and their partners' perception of perceived sexual appeal (19, 23, 24). Correspondingly, a patients' partner status has to be considered (single, partnered or widowed). Couples' relationships could be impacted by illness when communication with the partner is poor (25). Unpartnered patients may have substantial concerns about changes in body image and how to notify a new partner about the cancer and its' consequences.



**Figure 1.** Dimensions of sexuality.

Source Tierney DK. Sexuality: A Quality-of-Life Issue for Cancer Survivors. *Seminars in Oncology Nursing*. 2008;24(2):71-9. (21).

### ***Treatment characteristics***

Surgery is frequently part of cancer treatment but may lead to sexual dysfunction resulting from nerve damage, temporary or permanent body deformation, changes in bowel or bladder function and physical weakness (26-28). Body image, for its part, plays a substantial role as a part of mental health and sexual function (29, 30). Radiation effects can deteriorate sexual function due to connective tissue fibrosis (e.g. vaginal stenosis), skin changes and tenderness, (chronic) pain, nerve damage, lymphedema, altered bladder and bowel function, fatigue, ovarian failure, erectile dysfunction due to small-vessel injury and ejaculatory issues (31-37). Furthermore, radiation can have a negative impact on long-term cosmetic outcomes in breast cancer (38, 39). Chemotherapy has the ability to cause mucositis, which induces vaginal irritation, lubrication issues and pain with intercourse (40, 41).

Furthermore, short and long term effects like nausea, fatigue, hair loss, erectile dysfunction and premature menopause may also result in altered sexual function (42-44). In women, antihormonal therapy is associated with a lower frequency of sexual activity, less satisfaction and more discomfort during sexual activity (45, 46). As for men, typical side effects like hot flashes, gynecomastia, loss of libido, erectile dysfunction and fatigue may occur from androgen deprivation therapy (47, 48).

### ***Sexual health care needs***

Due to the increase in the number of cancer survivors, attention for cancer survivorship is increasing correspondingly. For most patients, cancer survivorship includes maintaining a satisfactory quality of life, along with the ability to function appropriately sexually (49). However, sexual function is not only an issue for patients treated with curative intent. Palliative patients unanimously agreed that care should include the counselling of the impact of their illness on sexual function and are often even more affected than other cancer patients (50-52). Nonetheless, for various reasons, sexual function is frequently omitted and underreported by oncology health care professionals (53-60). Patients and their partners may find it challenging to initiate questions about sexual function, although a significant group would be interested in receiving sexual counselling (61, 62). Few cancer patients recall discussing possible sexual side effects before commencing their treatment. Neither do they remember discussing treatment options for sexual issues after treatment (26, 56). Coping with sexual concerns during and after cancer treatment seems to remain a delicate business for health care professionals, patients and their partners. A surge of literature has come up in the past decade highlighting the importance of sexual function in cancer patients. To which amount consideration is paid to sexual concerns of cancer patients in the Dutch oncology practice remained unidentified so far and hence the incentive for this thesis.

Fertility impairment due to cancer treatment

Cancer treatment may result in impaired fertility and influence family planning in patients of reproductive age (defined by the WHO as 15-49 years) (63). In the Netherlands, close to one in ten cancer diagnoses affects an individual of reproductive age (64). Not only will various cancer treatments alter reproductive potential in groups like testicular cancer and lymphoma patients, but fertility may also already be decreased before treatment has started (65-68).

Treatment characteristics

Systemic chemotherapy targets rapidly dividing cells, and as a result, gonadal function may be impaired after treatment (69, 70). Radiotherapy causes ionising harm to primordial and growing follicles in the ovary, spermatogonia in the testes or the hypothalamic-pituitary-gonadal axis (71, 72). Furthermore, due to total body irradiation or pelvic radiotherapy, the uterus' vascularisation may be harmed, leading to an increased risk of miscarriage, low birth weight infants and premature births (73). Female cancer survivors have 39% less chance of becoming pregnant than the general population, as depicted in Figure 2 (74). Future fertility perspectives are somewhat better in male survivors, with a 26% lower post-cancer pregnancy rate in comparison with the general population (74).

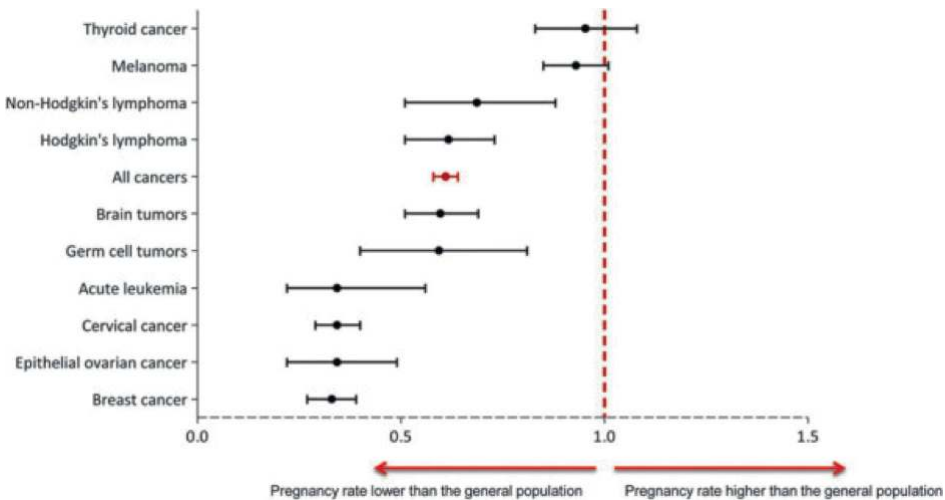


Figure 2. Chances of subsequent pregnancy depend on the type of cancer—analysis adjusted for age, previous parity and level of education. Data adapted from a population-based study from Norway, which included 16 105 female cancer survivors and 85 500 controls (74).

Source Peccatori FA, Azim HA, Orecchia R, Hoekstra HJ, Pavlidis N, Kesic V, et al. Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up†. Annals of Oncology. 2013;24:vi160-vi70. (75).



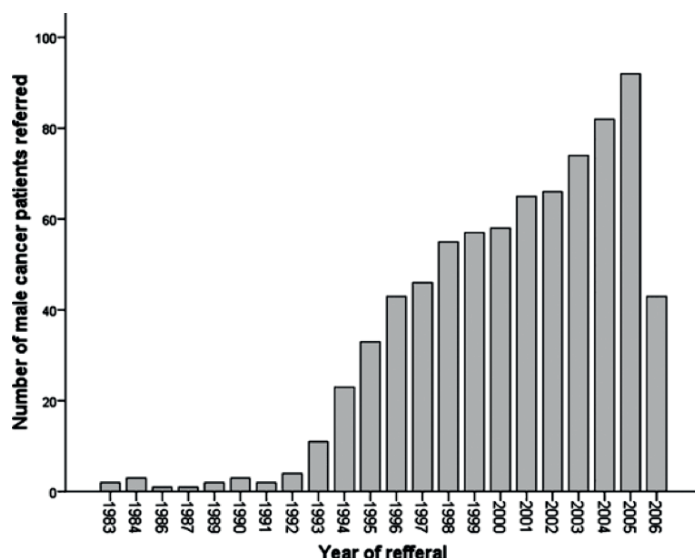
### ***Fertility preservation***

A variety of options has come available in the past decades, providing us with rapid and effective methods to cryopreserve gametes, embryos and reproductive tissue for patients about to commence cancer treatment (76). For males who are scheduled for treatments that may affect their chances of future fertility, sperm cryopreservation should be performed before treatment initiation (77). Sperm cryopreservation is considered the most cost-effective strategy for fertility preservation in male cancer patients (78). If sperm cryopreservation is not possible due to sperm abnormalities, testicular sperm extraction (TESE) is available (79). Young women desiring future fertility have embryo or oocyte cryopreservation options as the main available methods to preserve fertility, yet ovarian stimulation may take up to three weeks (80). Freezing ovarian tissue is an alternative without causing cancer treatment delay as it does not require ovarian stimulation but implies two surgical interventions and is still considered experimental (81). In the case of pelvic radiation, ovarian transposition can be considered. However, this does not protect the uterus from radiation-induced damage (82). In some cases, there may be an advantage of combining different preservation approaches (80).

### ***Counselling and decision-making in fertility concerns***

Several international guidelines, networks and foundations have been established in recent times, highlighting the importance of timely discussion of potential fertility deterioration resulting from cancer treatments (75, 76, 80, 83). Despite these developments, practice behaviour and attitudes of health care professionals have been reported to vary, influenced by several barriers to discussing this delicate subject with cancer patients of reproductive age (5, 84-86). Among clinicians, knowledge of fertility-preserving options and when they should be offered is suggested to be varying and not always clear (87-89). In a survey among 560 women of reproductive age who received treatments that could potentially harm fertility, 61% was counselled by their oncology health care professionals, 5% by a fertility specialist and 4% performed fertility preservation (90). A review regarding fertility concerns in cancer survivors mentioned a recall for counselling fertility risks ranging from 34 to 72% (86). Fortunately, a positive trend regarding referral for semen cryo-preservation has been demonstrated, as the number of male cancer patients substantially increased during the past decades, as shown in Figure 3 (68).

The long-term emotional impact of not being able to conceive a child is a severe source of distress to people treated for cancer during childbearing age (91). Loss of fertility is the most distressing long-term outcome of cancer treatment and linked with reduced quality of life and mental health issues (91, 92). Although literature demonstrated that future fertility is a major concern for men and women diagnosed with cancer, insufficient knowledge and attitudinal barriers among health care professionals may prevent patients from receiving the required care and referral to a fertility specialist (86).



**Figure 3.** The number of men referred for semen cryopreservation according to the year of referral.

Source van Casteren NJ, Boellaard WP, Romijn JC, Dohle GR. Gonadal dysfunction in male cancer patients before cytotoxic treatment. *International Journal of andrology*. 2010;33(1):73-9. (68).

Considering the significant consequences of losing reproductive opportunities, health care professionals should be knowledgeable about fertility impairment associated with cancer treatment and proactively counsel fertility and preservation options with all patients of childbearing age (93). Counselling about reproductive loss and fertility preservation by the treating physician and a fertility specialist is associated with less regret and greater quality of life for cancer survivors (90). Oncology clinicians play an essential role in future reproductive abilities by working closely with fertility specialists, providing patients with extensive information about fertility preservation options before the start of cancer treatment.

The intention emerged to investigate whether patients are well informed about infertility risks and fertility preservation options and if sufficient support is provided for guiding them in their reproductive decision-making before treatment. By assembling this knowledge from the perspective of both doctors, nurses and patients, recommendations can be composed for improvements in clinical care for this vulnerable group at risk of losing their reproductive capability.

## OUTLINE OF THIS THESIS

This thesis is divided into two parts. **The first part** focuses on discussing the effects of cancer and its treatment on sexual functioning by oncology health care providers. The main research questions concerned to what extent concerns regarding sexual function are discussed and per-

ceived barriers to the consultation of sexual function. Other objectives included determining the responsibility for discussing sexual function and potential problems, present knowledge and interest for additional training. Quantitative, nationwide evaluations have been performed among oncology health care professionals in pursuance of addressing these research questions. We evaluated Dutch oncology nurses, surgical oncologists, radiation oncologists, medical oncologists, urology residents and plastic reconstructive surgeons. Furthermore, urology and radiation departments have been approached in order to investigate the current information provision and counselling with regards to sexual function and prostate cancer treatments.

Following the assessment of the discussion of sexual function, the question arose regarding the management of fertility issues in oncology practice. For this reason, **the second part** of this thesis focuses on the counselling of altered fertility due to cancer treatment. We aimed to investigate both patients' and health care professionals' perspectives on fertility-related issues. Data displayed in the second part have also been collected using questionnaires among both health care professionals and testicular cancer patients. We assessed the current practice of oncology nurses and medical oncologists in the counselling of impaired fertility with their patients. Furthermore, the current level of knowledge regarding the influence of cancer drugs on reproductive and sexual function was examined among medical oncologists.

Finally, **in part three**, the findings of the work presented in this thesis are discussed and placed in a broader perspective. Moreover, future perspectives are represented. Summaries of the studies reported in this thesis are provided in both English and Dutch.

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# PART I

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**Sexual health communication between cancer  
patients and oncology clinicians**

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# Chapter 2

*Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses*

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## INTRODUCTION

For most types of cancer, regardless of the patient's age or relationship status, the disease and its treatment can lead to a deterioration in sexual health (Baker et al., 2005; Beckjord et al., 2011; Den Oudsten et al., 2012; Galbraith and Crighton, 2008; Hughes, 2008; Lange et al., 2009; Sadovsky et al., 2010; Wright et al., 2002). The World Health Organisation has addressed sexual health as an integral aspect of wellbeing, 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. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence' (World Health Organization, 2006). Sexual health cannot be defined without considering sexuality, partially defined as 'a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction' (World Health Organization, 2006). Satisfactory sexual function (SF) (i.e. sexual health despite the presence of disease) is considered to make an important contribution to the quality of life of cancer patients (Flynn et al., 2011; Krebs, 2008; Stead et al., 2003). The disease, however, frequently interferes with SF, leading to sexual dysfunction (SD). With rising long-term survival-rates for cancer, quality of life, including sexual health, is becoming increasingly significant. For instance, a reasonable SF provides the patient with the ability to participate in intimate relationships and accordingly assimilate the rehabilitation of self-esteem and physical body function.

Causes of a deterioration in SF in cancer patients are often physically and mentally ambiguous. Surgery, chemotherapy, hormonal agents, radiation therapy, intrinsic disease and psychological disease-related or body image factors may all contribute to a decrease in SF. Despite the fact that it is considered important by both patients and health professionals, patients and survivors have indicated that SF is frequently not addressed by oncology health care providers and an unmet need for information exists (Flynn et al., 2012). According to multifarious studies, compromising data on self-reported practice attitudes and observed practice attitudes, discussing SF with patients is not routinely performed by multidisciplinary oncology health care providers (Flynn et al., 2012; Gamel et al., 1995; Hautamaki et al., 2007; Hordern and Street, 2007; Julien et al., 2010; Kotronoulas et al., 2009; Lavin and Hyde, 2006; Nakopoulou et al., 2009; Olsson et al., 2012; Oskay et al., 2014; Stead et al., 2003; White et al., 2011; Zeng et al., 2011).

Oncology nurses are in a strategic position to be able to address SF, since they have frequent contact with patients when they can provide medical and emotional support for issues of concern during illness, treatment and recovery. Consequently, they are able to identify changes and provide information about the effect of the disease and its treatment on SF. The Oncology Nursing Society (USA) stated in 1979 that sexual health is an integral aspect of quality care in outcome standards for cancer nursing practice (Valencius et al., 1980). The first Dutch na-



tional guideline on SF was accepted by the Comprehensive Cancer Centre of the Netherlands (IKNL) in 2006, describing the important position of the oncology nurse in diagnosing and intervening in cancer-related SD (Integraal Kankercentrum Nederland, 2006).

Although discussing SF is officially stated as an important component of oncology nursing practice worldwide, many nurses experience barriers in actually discussing psychological or physiological aspects of SF. Barriers identified in previous publications involved factors like incorrect assumptions regarding sexual issues, discomfort, lack of knowledge (Kotronoulas et al., 2009), 'it is not my responsibility', embarrassment (Stead et al., 2003), patients do not expect nurses to discuss sexual concerns, confidence (Julien et al., 2010), lack of training, difficult to bring up the subject and lack of time (Hautamaki et al., 2007). Furthermore, it was shown that cancer patients, who themselves had to initiate discussion with an oncology professional about SF, already experienced significantly greater SD than those who did not bring up the subject (Flynn et al., 2012). The fact that routine nursing practice currently neglects addressing SF is emphasized by patients who state that more attention should be paid to SD (Hill et al., 2011; Hordern and Street, 2007; Stead et al., 2003). While health care professionals do little to address SF (Bekker et al., 2009, 2011; Nicolai et al., 2013; Saunamaki et al., 2010), patients with all types of cancer are willing to talk about their sex lives and the impact of the disease on their SF (Ananth et al., 2003; Hill et al., 2011). For over thirty years, international nursing and treatment guidelines have highlighted the importance of discussing SF and providing additional information. In their daily practice, however, nurses often avoid responding or fail to respond to patients' sexual concerns. Considering the incidence, the influence on quality of life and the patients' need to discuss the impact of disease on SF, there is much room for improvement in sexual health care provision in oncology departments.

Our aim was to investigate nurses' knowledge about and opinions on the responsibility for addressing SF in oncology treatment settings in The Netherlands, as well as looking at their attitudes to the subject and identifying what they consider as barriers to addressing it. In addition, the possible wish of oncology nurses for supplementary education and practical training in counselling on sexual matters was investigated. Several previous studies have recommended future research using a larger sample, in order to have a more representative overview. Since conflicting findings have been reported worldwide and as the studies performed have been mostly qualitative, based on a single centre and relatively small samples, we considered it essential to investigate the Dutch nurses' attitudes and practice behaviour in a nationwide quantitative study design (Kotronoulas et al., 2009). We postulated that most Dutch oncology nurses are aware of the possible impact of cancer diagnosis and treatment on SF, but they do not routinely take a sexual history because of difficulties in bringing the subject up and stereotypical assumptions about sexuality in the face of cancer. This study was performed as part of an extensive study on possible omissions regarding attention paid to SF in oncology care, in order to develop sexual health care solutions for cancer patients in future.

# METHODS

## Study design

Data for this cross-sectional survey were collected using a questionnaire. The sample consisted of Dutch nurses involved with oncology patients working in various departments in several clinical settings. Our sampling strategy aimed to be representative with regard to tumour site, employment setting, level of education, years of oncology experience, type of hospital, age and gender.

## Instrument design and development

The established Sexuality Attitudes and Beliefs Survey (SABS) assesses nurses' attitudes to and views on human sexuality with 12 items presented in a Likert-type format (1-6 levels of agreement) (Reynolds and Magnan, 2005). In order to acquire extensive information on all relevant factors covering the aim of this study, not included in the SABS, it was decided to design a more comprehensive questionnaire. The current questionnaire design does, however, comprise items addressed in the SABS. The 37-item questionnaire was developed by the corresponding author (E.M.K.) in cooperation with an expert-panel, consisting of an experienced sexology researcher (M.P.J.N.), a urologist-sexologist (H.W.E.), a professor of oncology (S.O.) and an oncology research nurse (A.Q.M.J.v.S). A literature review was conducted to find other surveys in the field of nursing and sexuality, in order to merge all relevant items, barriers and what was not yet known. The design made use of previous surveys among health care providers (Bekker et al., 2011; Nicolai et al., 2013), studies which measured adequately attitudes regarding sexuality. After the initial instrument design, the authors individually scored all items for content validity. Items scored as non-essential by multiple authors were removed. The pilot questionnaire was reviewed by 10 anonymous oncology nurses from the LUMC (Leiden University Medical Centre) and modified using their feedback. In the pilot, the questionnaire was tested for length, layout, linguistic inaccuracies, identification of problematic questions, advice on content, whether response choices were appropriate and whether respondents followed directions. On the basis of the pilot, irrelevant questions were removed and minor linguistic changes and question order modifications made.

The final version comprised a demographic sheet and Likert scale items (ranging from 1 to 5 levels of agreement) measuring practices, attitudes, content of sexual counselling, responsibility, need for education and barriers regarding discussing SF and fertility issues. Demographic data included professional background, experience in oncology practice, gender and age. Internal and external barriers, which, on the basis of literature, were assumed to be present, included patients' age, partnership, culture, language, privacy, state of disease, prognosis and other possible restraints. All results were compared, taking into account demographic respondent information which might be relevant, such as age, gender, experience and knowledge. We also investigated the existence of local protocols and perceptions concerning the responsibility for addressing SF, in order to clarify whether or not this is indeed a nursing responsibility. All

responses were processed anonymously. Questionnaires were included for analysis when the participant had completed at least the most relevant items. These were the demographic characteristics and the questions on practice patterns regarding how often sexual counselling took place, as this was the main outcome. Data concerning fertility issues were processed separately.

## Reliability

Two questions with 5 Likert scales on the subject, how often do nurses address sexual health with new patients compared to follow-up settings, had a Cronbach's alpha of 0.80. Scores on reliability of two questions with 5 Likert scales regarding nurses knowledge about SF also demonstrated good internal consistency (Cronbach's  $\alpha = 0.80$ ). The Cronbach's  $\alpha$  scores for the subscales on matching barriers ranged from 0.61 to 0.91, respectively, with 2-3 barriers in every corresponding dimension and 5 Likert scales per item. Items corresponded as far as cultural/religious/ethnic and language barriers were concerned, knowledge and complexity, barriers addressing embarrassment and barriers to raising the topic.

## Survey administration

The questionnaire was available as a web-based and a paper version. The web-based version was promoted on several online Dutch oncology nursing platforms, including that of the Dutch Oncology Nursing Society, relevant social media groups and the website, [www.nursing.nl](http://www.nursing.nl). The link was e-mailed to all available addresses of hospitals and oncology nursing departments throughout The Netherlands with the request to distribute this amongst employed oncology nurses. Web-based data were collected from September 2012 to December 2012. The paper version was handed out during the annual Dutch Oncology Nursing Congress held in Ede on 27-28 November 2012 and delegates (with the exception of those nurses who had already participated via the Web) were asked to complete the questionnaire before leaving the congress. Recruiters at the Congress approached nurses in order to obtain informed consent. Nurses who had already participated via the Web did not receive a copy. Each nurse who participated during the Congress received a book on cancer and sexuality. Data from the web-based survey and the congress survey were processed together. The ten responses from the pilot survey were added to the final analysis group, since these nurses completed all answers and only small modifications had been made.

## Statistical methods

Data analysis was performed using SPSS (Release 20.0; SPSS Inc.). The internal consistency of the questionnaire was measured using Cronbach's coefficient  $\alpha$ . The results were described using frequency distribution. Observed differences between demographic information and specific answers were identified using the Pearson's chi-square test; McNemar's test was applied for paired nominal data. Comparison between demographic information from congress respondents and web-based respondents was performed with the Student's t-test and Pearson's chi-square test. P-values  $< 0.05$  were considered statistically significant.

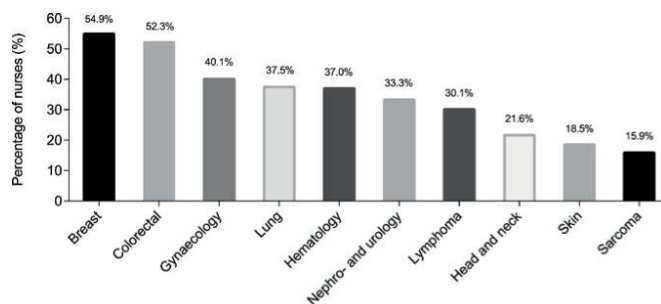
## Ethical considerations

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 in order to verify whether ethical approval was necessary. As the study did not concern any information recorded by the investigator in such a manner that subjects could be identified, directly or through identifiers linked to the subjects, and as it did not compromise the study participants' integrity, the Committee declared that no formal ethical approval was needed (Bekker et al., 2011). However, ethical principles were taken into consideration. With regard to the principle of autonomy, participation in the survey was completely voluntary. Information was provided about the study aims and highlighted the anonymous nature of the survey. Each respondent had to state approval before participating and an opt-out possibility was implemented. The principle of justice, beneficence and non-maleficence are not applicable, since the survey does not involve an actual intervention. The anonymous survey does not harm or benefit the nurses in any way.

## RESULTS

### Participants

The sample consisted of Dutch nurses involved with cancer patients working on various departments in several clinical settings, as defined in Fig. 1 and Table 1. A total of 431 nurses completed the survey and were included in this study. A further 46 questionnaires were completed as far as the most relevant items were concerned; these were also included. All other incomplete forms were excluded from analysis; note that these incomplete forms were submitted by the group using the web-based version. 128 nurses (26.8%) were recruited during the congress, 339 questionnaires (71.1%) were collected via the website, 10 nurses (2.1%) were included from the LUMC pilot, making a total of 477 eligible respondents. For accurate information about study design, respondents and reasons for refusal, see the study flow chart displayed in Fig. 2.



a) Please note that some nurses were employed at multiple departments and some nurses did not specify an area of expertise.

Fig. 1. Distribution of nurses in relation to the areas of expertise, classified by tumour site (n = 459).

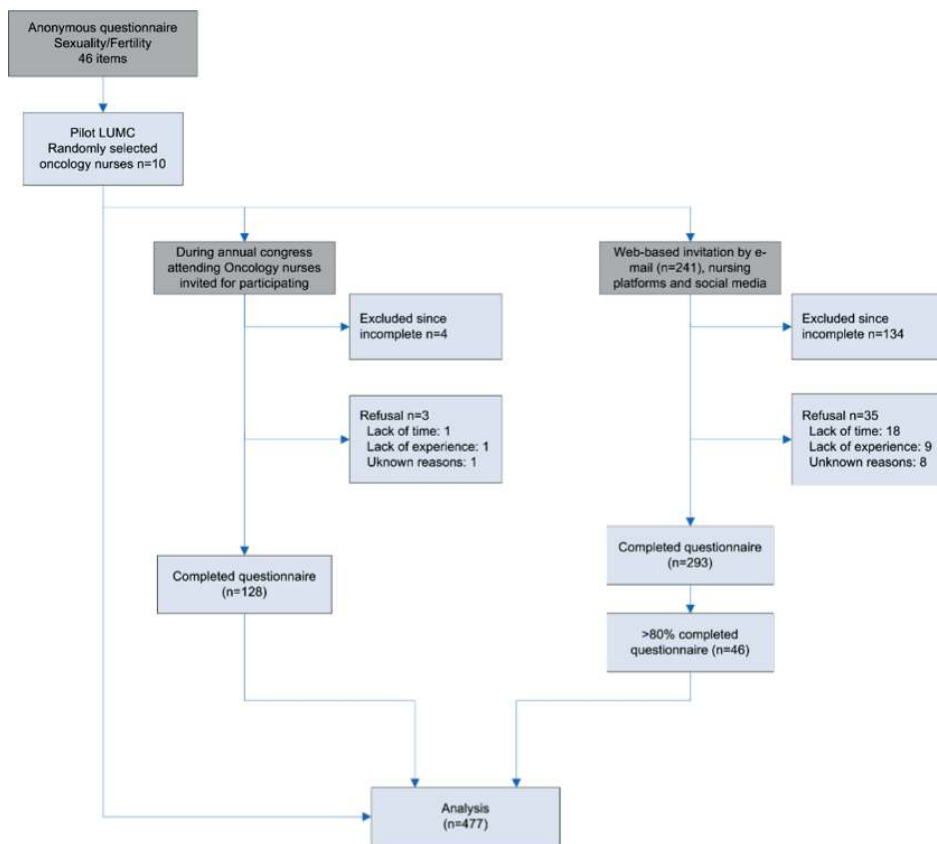


Fig. 2. Study flow diagram showing study design and respondents/non-respondents.

## Participant characteristics

Demographics from the congress and the online data sets were compared; no significant differences were found concerning age ( $p = 0.73$ ), gender ( $p = 0.23$ ), type of hospital ( $p = 0.31$ ), function ( $p = 0.27$ ) or experience ( $p = 0.66$ ). Small differences were seen regarding areas of expertise (classified by tumour site), as slightly more nurses recruited during the congress had expertise in haematology (46% versus 33%;  $p = 0.01$ ), nephrology and urology (41% versus 31%;  $p = 0.03$ ), gynaecology (47% versus 37%;  $p = 0.04$ ) and head and neck oncology (28% versus 19%;  $p = 0.04$ ). There was no significant difference in distribution of other areas of expertise among the respondents ( $p$  ranged from 0.07 to 0.41). All participants were oncology nurses, a considerable number of whom had a degree (22.9%). The majority of the nurses were female (90.8%), their ages ranging from 19 to 62 years (median = 44 years). The demographic details are outlined in Table 1. See Fig. 1 for the distribution over areas of expertise in oncology.

**Table 1.** Demographic characteristics of participating nurses.

Demographic characteristics (n=477)	n (%)
<b>Age (years)</b>	460 (96.4)
Median 44 years (range 19-62)	
<b>Gender</b>	
Male	30 (6.3)
Female	433 (90.8)
Unknown	14 (2.9)
<b>Oncology experience (years)</b>	
<1	13 (2.7)
1–2	32 (6.7)
3–5	89 (18.7)
6–10	87 (18.2)
11–15	92 (19.4)
>15	150 (31.4)
Unknown	14 (2.9)
<b>Employment setting</b>	
Registered nurse <sup>a</sup>	84 (17.6)
Registered nurse currently in Oncology registration training	22 (4.6)
Registered nurse with Oncology certificate <sup>b</sup>	215 (45.1)
<i>Clinical setting</i>	
• Inpatient	92 (19.3)
• Outpatient	105 (22)
• In/out-patient	18 (3.8)
Registered nurse with graduate degree <sup>c</sup>	109 (22.9)
Nurse in charge of Oncology department <sup>d</sup>	10 (2.1)
Research nurse	7 (1.5)
District nurse with Oncology specialism <sup>e</sup>	8 (1.6)
Different/unknown	22 (4.6)
<b>Hospital type</b>	
University hospital	163 (34.2)
District general teaching hospital	141 (29.6)
District general hospital	149 (31.2)
Extramural	8 (1.6)
Unknown	16 (3.4)

a Involved vocational trained nurses as well as bachelor's degree nurses with no registered specialism but currently employed in an oncology department.

b Involved nurses with official Oncology registration (acknowledged by the Dutch board of Hospital Education) following 1 year official Oncology training.

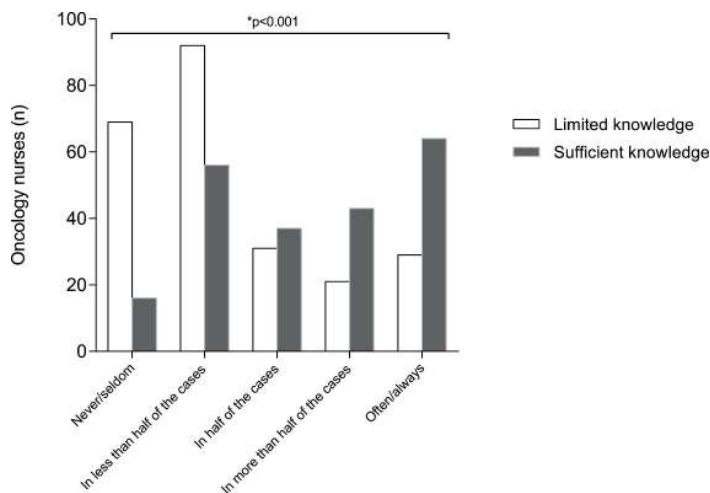
c Involved nurses with a graduate degree from a University of Professional Education or a University of Science, usually involved with in- and outpatient departments.

d Clinical setting undefined.

e Involved nurses caring for cancer patients at home.

Practice patterns

Participants believed that, in general, 69.7% (SE 1.4) of cancer patients experience some kind of altered SF due to disease and/or treatment (n = 265). The oncology nurses were asked whether or not they routinely asked about SF and how often they thought the oncologists discussed SF; several other practice patterns were also explored. Regarding the question ‘How often do you discuss SF?’ nurses indicated the following statistics: never/rarely: 18.9%; in less than half of the cases: 32.6%; in half of the cases: 15.1%; in more than half of the cases: 13.4%; and often/always: 20%. Oncology nurses >44 years discussed SF significantly more often than nurses ≤44 years (Pearson Chi-Square, p = 0.009). Graduate oncology nurses discussed SF significantly more frequently compared to the other nurses (Pearson Chi-Square, p < 0.001). Moreover, experienced nurses (>10 years in oncology practice) discussed SF significantly more often than less experienced nurses (Pearson Chi-Square, p = 0.001). An equally strong correlation was found between level of knowledge and discussing SF (Fig. 3). Nurses with the self-scored knowledge levels ‘not any’, ‘not so much’ and ‘some’, discussed SF less often than nurses with ‘sufficient’ and ‘a lot’ of knowledge (Pearson Chi-Square, p < 0.001). Seventy-four percent of the nurses estimated that the oncologist never, rarely or in less than half of the cases discussed SF with the patients. Further data about practice attitudes regarding SF are featured in Table 2.



**Fig. 3.** Level of knowledge about sexual dysfunction following cancer in relation to the frequency of discussing sexual function (p < 0.001 Pearson Chi-Square, n = 458).

**Table 2.** Frequency distributions on questions in relation to discussing sexual function.

Items: How often...	Never/ Rarely	Less than half of the cases	Half of the cases	More than half of the cases	Often/ Always
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Do you discuss SF of the patient	90 (18.9)	155 (32.6)	72 (15.1)	64 (13.4)	95 (20)
Do you think that SF is discussed with the oncologist	144 (30.2)	211 (44.2)	73 (15.3)	37 (7.8)	12 (2.5)
Patients present SF complaints spontaneously	261 (56.4)	170 (36.7)	19 (4.1)	8 (1.7)	5 (1.1)
Do you make sure that SF is discussed with a new patient	109 (23.7)	110 (23.9)	56 (12.2)	77 (16.7)	108 (23.5)
Do you discuss SF during check-up appointments	187 (43.1)	120 (27.6)	48 (11.1)	38 (8.8)	41 (9.4)
Is the partner of the patient present during SF conversation	55 (12.6)	101 (23.1)	75 (17.2)	107 (24.5)	98 (22.5)
Do you ask about the sexual orientation of the patient	297 (68.1)	55 (12.6)	16 (3.7)	25 (5.7)	43 (9.9)
Do you discuss contagiousness of cancer with the patient	250 (59.5)	65 (15.5)	22 (5.2)	33 (7.9)	50 (11.9)
Do you discuss transmitting chemo agents during intercourse	110 (26.1)	51 (12.1)	39 (9.2)	58 (13.7)	164 (38.9)

Depending on the type of treatment, significant differences were observed in percentage of nurses discussing SF: treatment with intent to cure, 83.2% ( $n = 396$ ); life-prolonging treatment, 57.1% ( $n = 272$ ); and palliative treatment 44.5% ( $n = 212$ ) (McNemar's test  $p < 0.001$ ). With regard to age, results show that oncology nurses never/rarely discuss SF with patients aged 66-75 years (60.8%,  $n = 472$ ) or those over 76 years (73.1%,  $n = 465$ ). For younger patients, a majority of the oncology nurses said they discussed SF regularly/often: in 60% of patients aged 16-35 years ( $n = 467$ ), 63.1% of those aged 36-50 years ( $n = 470$ ) and 57.2% of the 51-65-year age group ( $n = 473$ ).

## Responsibility

The majority of oncology nurses (87.6%) agreed that the oncology nurse is responsible for discussing SF as far as disease-related and treatment-related problems were concerned. An almost equal majority (88.7%) stated that the oncologist also bears responsibility for discussing SF. On the other hand, 42% of the nurses considered it to be the patient's responsibility to raise their sexual concerns during a consultation ( $n = 469$ ).

## Availability of local policy or agreement

55.4% of the respondents noted that a local policy or agreement was in place for discussing SF as standard routine. Approximately a third of the nurses (29%) stated there was no such agreement or policy in place and 15.6% reported that they did not know if their department had such a policy. According to 31.3% of the nurses, it was policy to inform patients about



treatment-related sexuality issues. Only 24.1% of the nurses reported that the department policy stated that sexuality should be discussed throughout treatment (n = 469). Nurses in such a department discussed SF with their patients significantly more frequently (Pearson Chi-Square,  $p < 0.001$ ). The majority of respondents (85.8%) stated that SF is not discussed in a multidisciplinary consultation (n = 416).

### Knowledge and training

Regarding knowledge levels, a majority stated they had ‘some knowledge’ or ‘sufficient knowledge’ about SD related to oncological illness (41.7% vs. 38.2%). An almost equal number of nurses stated they had ‘some knowledge’ or ‘sufficient knowledge’ about treatment-related SD (38.9% vs. 42.5%). However, in response to the questions concerning solutions for SD, 47.9% reported having ‘some knowledge’, 24.8% reported having ‘not so much knowledge’ (n = 459). In answer to the question ‘Would you like to acquire more knowledge on how to address sexual issues?’ 76.3% replied positively (n = 422). 63% of the nurses stated that current oncology training does not sufficiently cover the assessment of SF (n = 400).

### Techniques for discussing SF

With a view to broaching the subject of SF, 71.3% of the nurses stated they only addressed the issue of possible sexual side-effects and 43.3% stated they only informed the patient rather than questioning him/her. A further 40.5% stated they only discussed SF if the patient mentioned the subject (n = 443). A small group reported using humour (20.5%). More than half of the nurses (n = 438) enquired about fatigue (65.1% in female, 59.8% in male) and insecurity due to altered self-image (56.4% in female, 42.3% in male). Less than a third of the nurses asked their female patients if vaginal dryness was a problem (28.5%), but 51.7% of the nurses asked male patients about erectile dysfunction. We also asked about the availability of written information for patients. Over half of the nurses stated that such information is not available in their department (56%, n = 441).

### Barriers

The oncology nurses were given a list of possible barriers to discussing SF, in order for them to indicate the extent to which they agreed (Table 3).

Nurses mentioned ‘lack of training’ as a major barrier (42%). The second barrier, with which 41.2% of the nurses agreed, was ‘presence of a third party’. Other barriers, with agreement by about a third of the respondents, were ‘no angle or motive for asking’ (32%), ‘advanced age of the patient’ (30.8%) and ‘language/ethnicity’ (30.3%). The least consensus was reached on the barriers: ‘colleagues think it is inappropriate if I discuss SF with patients’ (1.1%) and ‘patient is the same gender’ (1.4%).

**Table 3.** Frequency analysis on barriers in relationship to discussing sexual function.

Items: Barriers in discussing sexual function <sup>a</sup>	Totally agree	Agree	Partly agree/ partly disagree	Disagree	Totally disagree
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Lack of training	32 (7.5)	148 (34.5)	123 (28.7)	93 (21.7)	33 (7.7)
Presence of a third party	22 (5.2)	153 (36)	121 (28.5)	103 (24.2)	26 (6.1)
No angle or motive for asking	15 (3.5)	121 (28.5)	126 (29.7)	109 (25.7)	53 (12.5)
Advanced age of the patient	15 (3.5)	117 (27.3)	127 (29.6)	124 (28.9)	46 (10.7)
Language/ethnicity	13 (3)	117 (27.3)	156 (36.4)	118 (27.5)	25 (5.8)
Culture/religion	8 (1.9)	117 (27.3)	159 (37.1)	116 (27)	29 (6.8)
Patient is too ill	17 (4.0)	105 (24.4)	134 (31.2)	130 (30.2)	44 (10.2)
Lack of knowledge	20 (4.7)	87 (20.3)	136 (31.7)	141 (32.9)	45 (10.5)
Patient doesn't bring up the subject	9 (2.1)	90 (21.1)	104 (24.4)	156 (36.6)	67 (15.7)
High complexity of sexual disorder	6 (1.4)	89 (21)	139 (32.9)	144 (34)	45 (10.6)
I feel uncomfortable	12 (2.8)	71 (16.7)	108 (25.4)	162 (38.1)	72 (16.9)
Patient is not ready to discuss sexual function	10 (2.3)	72 (16.7)	142 (33)	145 (33.7)	61 (14.2)
Lack of time	17 (4)	58 (13.5)	81 (18.9)	156 (36.4)	117 (27.3)
Sexuality is a private matter	4 (0.9)	67 (15.7)	134 (31.5)	160 (37.6)	61 (14.3)
Embarrassment	1 (0.2)	65 (15.3)	99 (23.3)	188 (44.2)	72 (16.9)
Concerned about making patient uncomfortable	0 (0)	52 (12.1)	113 (26.3)	192 (44.5)	73 (17)
Sexuality is not a patient's concern	3 (0.7)	48 (11.2)	128 (29.8)	173 (40.2)	78 (18.1)
Age difference between you and patient	5 (1.2)	45 (10.5)	62 (14.5)	226 (52.7)	91 (21.2)
Surviving is more important	4 (0.9)	45 (10.6)	130 (30.6)	168 (39.5)	78 (18.4)
Not relevant for all type of cancers	3 (0.7)	35 (8.3)	69 (16.3)	213 (50.2)	104 (24.5)
Afraid to offend the patient	1 (0.2)	37 (8.7)	99 (23.3)	212 (49.9)	76 (17.9)
Sexuality is not a matter of life and death	1 (0.2)	19 (4.5)	89 (20.9)	229 (53.9)	87 (20.5)
It's someone else's task	1 (0.2)	14 (3.3)	52 (12.1)	190 (44.3)	172 (40.1)
No confidence in treatment for sexual dysfunction	0 (0)	14 (3.3)	86 (20.2)	230 (54.1)	95 (22.4)
Patient is the opposite gender	0 (0)	13 (3.1)	40 (9.4)	230 (54)	143 (33.6)
Patient is the same gender	2 (0.5)	4 (0.9)	22 (5.1)	259 (60.4)	142 (33.1)
Colleagues think it's inappropriate if I discuss sexual function with patients	1 (0.2)	4 (0.9)	31 (7.3)	222 (52.0)	169 (39.6)

a Barriers sorted descending from most agreed (totally agree þ agree) to least agreed (disagree þ totally disagree).

## Importance

The importance of assessing SF in oncology patients was addressed at the end of the questionnaire (*n* = 414). A majority of the nurses (56%) considered the need to assess SF as 'important'; an additional number stated it was 'very important' (13.8%). The remaining respondents indicated it was 'important to some extent' (27.1%), 'not very important' (2.4%) or 'unimportant'.

ant’ (0.7%). According to the responding oncology nurses, patients with whom SF should be discussed hardly bears any relation to the tumour site (Table 4). Most nurses thought SF should definitely be discussed with breast cancer patients (95.7%) and gynaecological cancer patients (94.0%). By contrast, according to 2.6% of the nurses, it was not necessary to discuss SF. For a complete summary of the patients with whom sexuality should be discussed per type of cancer, see Table 4.

**Table 4.** Patients with who sexual function should be discussed according to respondents (n = 416).

Type of patients	Nurses agreeing sexual function should be discussed with these patients
	<i>n (%)</i>
Breast cancer	398 (95.7)
Gynaecological cancer	391 (94.0)
Urological cancer	368 (88.5)
Colorectal cancer	366 (88.0)
Haematological cancer	295 (70.9)
Head/neck cancer	293 (70.4)
Lung cancer	280 (67.3)
Nephrological cancer	277 (66.6)
Lymphoma	270 (64.9)
Palliative cancer care	262 (63.0)
Neuro-endocrine cancer	257 (61.8)
Sarcoma	255 (61.4)
Skin cancer	254 (61.1)
I do not believe it is necessary to discuss sexual function.	11 (2.6)

# DISCUSSION

## Key findings

This survey provides extensive data on routine practice regarding sexual health issues in a nationwide sample of Dutch oncology nurses. It also looks at the level of knowledge about these issues and the barriers to tackling them. Participating nurses estimated that the majority of cancer patients experience some degree of SD. Generally, a third of the oncology nurses enquire routinely about SF, depending on the patient’s age and type of treatment (curative vs. life-prolonging vs. palliative treatment). When questioned further, the nurses who did discuss SF stated they only addressed possible sexual side-effects or informed the patient rather than discussing the sexual concerns. Despite these practice patterns, a majority believed it was their responsibility, as well as that of the oncologist, to provide SF counselling. The strongest barriers

to discussing SF found in this study were lack of training, presence of a third party, no angle or motive for asking, advanced age of the patient and different language/ethnicity.

## **Comparison with other population data**

The findings support and extend previous research in western countries concerning reasons why oncology nurses do not routinely discuss matters of sexuality with cancer patients. Besides routine practice, this study describes various issues involved in the process of sexual counselling, which help to interpret the data. Previous studies had less-representative samples; they were small, based on a single-centre, unequal in age distribution, or included other health care workers in the sample (Kotronoulas et al., 2009). The present study describes a high rate of acceptance that SF consultation should be both the nurses' (87.6%) and the physicians' (88.7%) responsibility compared to earlier studies, in which nurses stated that addressing SF was not included in their task, with 62.5%-78% regarding it as being their responsibility (Hautamaki et al., 2007; Nakopoulou et al., 2009; Saunamaki et al., 2010). This finding might be the result of a growing awareness of the sexual burden in cancer patients within the last 20 years. However, the level of knowledge concerning SF remains unsatisfactory. We found a similar frequency of discussing SF as a recent study from Finland, in which a third of the oncology nurses stated they discussed SF fairly frequently, also influenced by work experience. Their cut-off point was, however, 2 years whereas ours was 10 years (Hautamaki et al., 2007). Factors influencing the provision of sexual counselling correspond to a previous study from The Netherlands, indicating that little has changed. Age, experience and knowledge also correlated positively with routinely addressing SF (Gamel et al., 1995). Julien et al. described that nurses aged younger than 40 years reported more barriers than older nurses. This is similar to our finding regarding nurses' age influencing incidence of discussing SF. In contrast to our data, in this sample, the level of education was not correlated with the barriers experienced in relation to sexual counselling (Julien et al., 2010). The main barrier, 'lack of training', matched other studies, where lack of training and lack of knowledge were given as the main reasons for not assessing SF. This supports our finding that adequate training is one of the main determining factors (Bekker et al., 2011; Gamel et al., 1995; Hautamaki et al., 2007; Nicolai et al., 2013). Contrary to findings in a Chinese oncology nursing study, time and 'sexuality is a private matter' are hardly mentioned as barriers in western studies (Zeng et al., 2011). It is helpful to realize that time is not a barrier for discussing SF, despite the current cost reductions which may result in an increased burden for health care providers.

## **Sexual counselling**

The present study reveals an apparent incongruity between treatment objectives and their implementation. Despite the fact it was relatively rare for nurses to take the initiative in discussing sexuality-related issues, the majority acknowledged that it is part of their job and also the responsibility of the oncologist. Not every patient needs extensive discussion about sexual

issues. We do, however, believe that as a part of informed consent for several treatments or as a result of disease, the issue should be addressed at some point. Furthermore, if the subject is simply addressed once, the patient can then decide themselves to bring it up again. The challenge is for the nurse to raise the subject, and if the patient expresses interest in discussing it, to do so. The strong association between the frequency of discussing SF and nursing experience, specialization and self-reported knowledge, supports the evident need for expanding educational activities. This is reinforced by a majority of the nurses stating they would like to acquire more knowledge, specifically about possible solutions for cancer-related SD. This survey did not take into account whether nurses had received any education on handling sexual issues in the past, an aspect which could be interesting in future survey research. During training, we recommend that the importance of discussing SF with cancer patients be highlighted, not only with the obviously affected patient (i.e. breast-, gynaecological-, urological- and colorectal patients). SF is also affected in other cancers, as it can deteriorate due to many causes including relationship issues, fatigue and changed appearance as a result of surgery or chemotherapy. Most nurses in this survey seemed aware that SF is of great importance in all forms of cancer; fewer believed that SF should be discussed with cancers not involving the breast, intestines or genitals. Lemieux et al. showed the importance of addressing SF even in a palliative treatment setting which unfortunately, according to our study, hardly ever happens, with a special role for the district nurse (Lemieux et al., 2004). Furthermore, a very important component is the presence of a local policy or agreement regarding initiating discussions on SF as a matter of routine. This study exposed the clear relationship between the availability of such a policy and the actual frequency of mentioning SF in a consultation. The considerable lack of availability and lack of awareness of local agreement on sexual counselling as a matter of routine should be a significant point of interest for heads of nursing departments.

Clearly, not every nurse should be forced into the role of sexual counsellor, since not everyone is able to discuss this controversial subject, for example because of private circumstances such as a bad sexual experience or religion. For this reason, considerable benefit could be derived by implementing a clinical nurse specialist on quality of life and sexuality, as investigated for gynaecological oncology purposes with successful results (Maughan and Clarke, 2001). Further research should investigate (1) the role other oncology health care providers could play in sexual counselling, (2) who could act as the coordinating staff member and (3) how to implement solutions beneficial to the unmet need for information.

## Study limitations and strengths

Possible limitations of this study demand some reflection. The results presented are of self-reported attitudes and those nurses who responded are more likely to be those already familiar with addressing sexual health issues. Efforts were made to ensure a more neutral response group by securing the anonymous nature of the survey, convincing nurses of the importance of this survey and providing a reward in the form of books in exchange for participation as

an incentive to motivate less-concerned nurses. The administered questionnaire was non-validated, since validated instruments like the SABS did not incorporate the main objectives and additional study aims (Reynolds and Magnan, 2005). In epidemiology, it is a well-known fact that re-using standard questionnaires will not necessarily point towards the exposure of interest, especially not when translated from another language (Silman and MacFarlane, 2002). However, all topics of the SABS were included and attempts were made to test for validity and reliability. The internal consistencies of the most important items of the questionnaire tested as acceptable to excellent. Test-retest reproducibility of the questionnaire was not tested; this was impossible due to the anonymous pilot design and study design.

Cultural, religious and partnership status of respondents were excluded in response to the pilot panel's decision; they felt they might have made the questionnaire too sensitive. Demographic particulars of the nurses indicated a heterogeneous sample regarding age and experience, although not for gender, since the majority were female. Comparison between the congress respondents and web-based respondents resulted in minor demographic differences regarding area of expertise; all other demographics were comparable. The Dutch Oncology Nursing Society currently has approximately 2400 members; hence the sample of 477 respondents in our survey is deemed sufficiently representative of the Dutch oncology nursing population (Bartlett et al., 2001). This is reinforced by the fact that the congress sample and the web-based sample were almost similar, suggesting our sample is a credible reflection of the total oncology nursing population. Finally, it was not possible to calculate the actual response rate, due to the combination of manual provision of questionnaires and the anonymous web-based design. The web-based survey revealed a high number of incomplete forms. Explanations for the high incompleteness rate are technical website issues and the anonymous web-based form which could not be continued at a later stage if time was short. Nor was it possible to estimate the extent of a non-response or a sampling bias. However, the interpretation of the response rate in general is questionable, since even a high response rate does not obviate a non-response bias (Barclay et al., 2002).

## CONCLUSION

Overall, the present study revealed that oncology nurses consider counselling on sexual issues to be an important responsibility, in line with discussing other side-effects caused by the disease or its treatment. Nevertheless, findings suggest that cancer patients may not routinely be receiving a sexual health evaluation by oncology nurses. While taking sexual histories on a routine basis is believed to enhance the quality of life, oncology nurses believed that oncologists address the subject rarely. The strongest barriers to discussing SF were lack of training, presence of a third party, no angle or motive for asking, advanced age of the patient and different language/ethnicity. Sexual counselling is provided significantly more often by nurses who have under-

gone further training, are more experienced, older, possess an academic degree and work in a department with a strict policy concerning SF. This emphasizes the potential effect of providing adequate knowledge and appropriate practice training. Policies and patient information regarding SF should be available in all nursing care units.

### **Implications for oncology nursing practice**

We sincerely hope that this study has emphasized the importance of discussing SD with all cancer patients and that the evidence presented will encourage nurses to address this often overlooked issue, thereby moving a step closer towards improving the quality of life of cancer patients. Oncological health care providers should agree on when and to which extent SF should be discussed, and in particular by whom.

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# Chapter 3

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

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## INTRODUCTION

Cancer patients commonly experience sexual problems, regardless of cancer origin or age of onset.<sup>1,2</sup> 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.”<sup>3</sup> 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.<sup>4</sup> 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.<sup>1,4,5</sup> 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.<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup> One-third of patients who have undergone major head and neck carcinoma treatment reported substantial problems with sexual interest and intimacy.<sup>9</sup> 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%.<sup>10</sup> Predictors for sexual dysfunction following colorectal surgery include preoperative radiotherapy, a stoma, complications during or after surgery and a higher age.<sup>10</sup> 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%.<sup>11</sup> Men with a colostomy reported erectile dysfunction in 79% of the cases, though a (temporary) colostomy affects sexual function in many ways.<sup>12</sup> 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.<sup>11</sup> Among patients with gynaecologic, breast or colorectal cancer, 37% received information about how surgery possibly affects their body image and sexual well-being.<sup>13</sup>

When it comes to bringing up the subject during a consultation with a physician, patients experience several barriers.<sup>14,15</sup> 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.<sup>16</sup> Knowing that most patients will not initiate a conversation about sexuality, health care providers carry the responsibility to address this issue.<sup>1</sup> Well-informed patients have an advantage in coping with consequences of surgery as complications are better tolerated if they are anticipated.<sup>17</sup>

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.<sup>18-21</sup> 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.<sup>20</sup>

## 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 <sup>a</sup>	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 ( $\geq 6$  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.

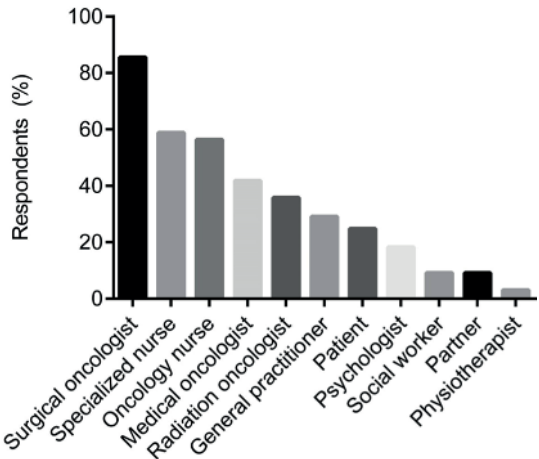
How often do you provide information regarding sexuality to patients who...	Never	Rarely	Regularly	Often	Always	Not applicable <sup>a</sup>
	<i>n (%)</i>					
	<i>n (%)</i>	<i>n (%)</i>		<i>n (%)</i>	<i>n (%)</i>	<i>n</i>
Will undergo breast surgery	21 (18.4)	54 (47.4)	22 (19.3)	11 (9.6)	6 (5.3)	30
Will (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 <sup>a</sup>	Partly agree/ partly disagree	Disagree <sup>a</sup>
	<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 <sup>a</sup>	Partly agree/ partly disagree	Disagree <sup>a</sup>
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.<sup>22</sup> 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.<sup>23</sup> 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.<sup>24,25</sup> Barriers found to the provision of sexual counselling were lack of time, limited experience and inadequate knowledge, in concordance

with our results.<sup>24,25</sup> 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.<sup>15</sup> 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.<sup>26</sup> 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.<sup>2</sup> 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.<sup>27</sup> 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.<sup>24</sup> On the contrary, cancer patients are willing to discuss sexuality and reported to be dissatisfied with the time spent discussing it.<sup>28</sup> 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.<sup>29</sup> 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?".<sup>30</sup> 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?".<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup> However, a high response rate will not necessarily result in a more illustrative sample and methods of boosting response rates may introduce further bias.<sup>34</sup> 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.

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# Chapter 4

## *Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist?*

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## INTRODUCTION

Cancer is a life-threatening disease, but because of expanding treatment options, it is turning into a condition with decreasing mortality. As patients live longer after diagnosis, attention for late effects of treatment and quality of life are of increasing importance, both during treatment and throughout survivorship [1]. A typical problem is that physicians and patients tend to concentrate on intensive medical treatment options and underestimate the late treatment-related adverse effects [2,3].

Radiotherapy (RT) is commonly used to treat cancer, whether as external-beam RT or brachytherapy. Specifically, pelvic RT for the treatment of uterine, cervical, bladder, prostatic, rectal, or anal cancer is known for its influence on sexual function, affecting both men and women [4,5]. Sexual dysfunction (SD) caused by pelvic RT originates from injury to organs, vessels, persistent inflammatory responses, hormonal deprivation, and psychologic responses, although the molecular etiology is not completely understood [6–13]. Tissue toxicity is depending on the accumulated radiation dose to the pelvic area [14–16]. Possible late effects of pelvic RT include pelvic fibrosis, resulting in endothelial damage, inflammation, ischemia, and eventually necrosis [17]. Vaginal discharge, skin erythema, and fatigue result in low scores of satisfaction with sexual function in women after pelvic RT [18–20]. Three years after RT for prostate cancer, 38% of pre-treatment potent men reported erectile dysfunction (ED), resulting in decreased satisfaction with sexual function [21]. Preoperative RT in primary rectal cancer has negative effects on sexual function in men and women [5]. RT on other areas of the body also has the ability to affect sexual function by inducing fatigue, psychosocial and emotional problems, sensory loss and reduced fertility [22], also breast radiation can have an impact on long-term cosmetic outcomes [23].

Despite the significant effect on sexual function, clinical assessment of treatment-induced SD following RT is an underexposed item during regular radiation oncologist consultations [24–26]. For this reason, patients should be actively informed on problems associated with radiation-induced SD and must be guided toward appropriate therapeutic options. To our knowledge, information concerning the attitude of radiation oncologists is barely available yet. So far, research focusing on radiation oncologists' attitudes regarding the provision of sexual counseling only involved a Chinese study [25]. However, the Global Survey of Sexual Attitudes and Behaviors revealed that women in East Asia were the least likely to talk to a doctor about their sexual issues (9% vs. 18–40% in non-Asian countries) [27]. For this reason, the Chinese survey might differ significantly from a non-Asian perspective.

As medical doctors are the major information source of treatment-induced morbidity and have a legal obligation to inform their patients on treatment-induced morbidity, investigating their current sexual counseling practices is of significant importance. By collecting data and demonstrating possible omissions, the development of a consistent and effective sexual health care counseling policy for patients receiving RT can be established. Aims The aim of this study was to investigate the attitude, knowledge, and barriers of Dutch radiation oncologists toward informing their patients on the possibility of treatment-induced SD. We also investigated the need for



training and perceptions concerning responsibility for addressing sexual issues, in order to clarify whether or not this is felt to be the radiation oncologist's responsibility. The data obtained could be used to adapt and develop educational training, guidelines and standard operating procedures regarding the counseling of cancer patients on treatment-induced sexual problems.

## **METHODS**

### **Study Design**

A cross-sectional postal survey was held among radiation oncologists and RT residents holding active practice in The Netherlands.

### **Cohort Identification and Survey Process**

Questionnaires were sent to all radiation oncologists and RT residents ( $n = 234$ ) who were member of the Dutch Association for Radiotherapy and Oncology (NVRO) at the time of Spring 2012. An information letter concerning the study and a postpaid return envelope were added, as well as an opt-out possibility. To facilitate the response rate, the initial mailing was followed by two reminders in August and November 2012. All data were collected anonymously in order to prevent a self-reporting bias.

### **Instrument Design and Development**

Identified participants were sent a 28-item questionnaire developed by the authors, content based on questionnaires successfully used for similar studies among cardiologists, urologists, surgical oncologists and oncology nurses in the Netherlands [28–31]. A pilot study with 24 radiation oncologists was performed to evaluate the questions and adjust the questionnaire for the final survey according to the comments. As a result of the pilot study, questions on practice attitudes were separated for tumor-specific areas of specialization, and participants were given the opportunity to answer for two different areas of specialization.

### **Data Analysis**

Quantitative data were analyzed using SPSS 20 (SPSS Inc., Chicago, IL, USA). The results were described using frequency distribution and descriptive statistics. Missing data (i.e., not completed questions) were not added with percentage calculations;  $n$  is always mentioned to clarify. Bivariate associations between demographic information and specific answers were made with Pearson's chi-squared test and Cochran-Armitage trend test.

### **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 in order to verify whether ethical approval was necessary. As the study did not concern any information recorded by the investigator in such a manner that subjects could be identified, directly or through identifiers linked to the subjects, and as it did not compromise the study participants' integrity, the Committee declared that no formal ethical approval was needed [32]. Participation was fully voluntarily and anonymous, an opt-out possibility was implemented.

### Main Outcome Measures

- Demographic questions relating function, experience, gender, age, and focus areas.
- Self-reported practice patterns regarding sexual counseling and providing information on sexuality.
- Opinion about responsibility for sexual counseling and referral behavior.
- Barriers toward assessing sexual health issues.
- Knowledge on sexual problems in reference to RT.
- Need for additional training.

## RESULTS

### Participants

Questionnaires were sent to 234 members of the NVRO. The final response rate was 54.6%, for further details on participation see Figure 1.

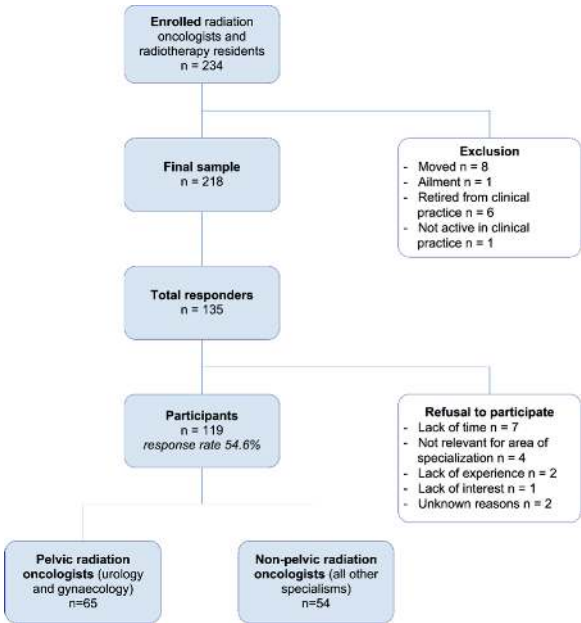


Fig. 1. Flow chart of the final participants.

## Demographics of Respondents

Overall, there was an almost equivalent amount of men and women with a median age of 47 years. There was variation in experience, 52.9% of all respondents had over 15 years of experience in RT. All demographic information is displayed in Table 1.

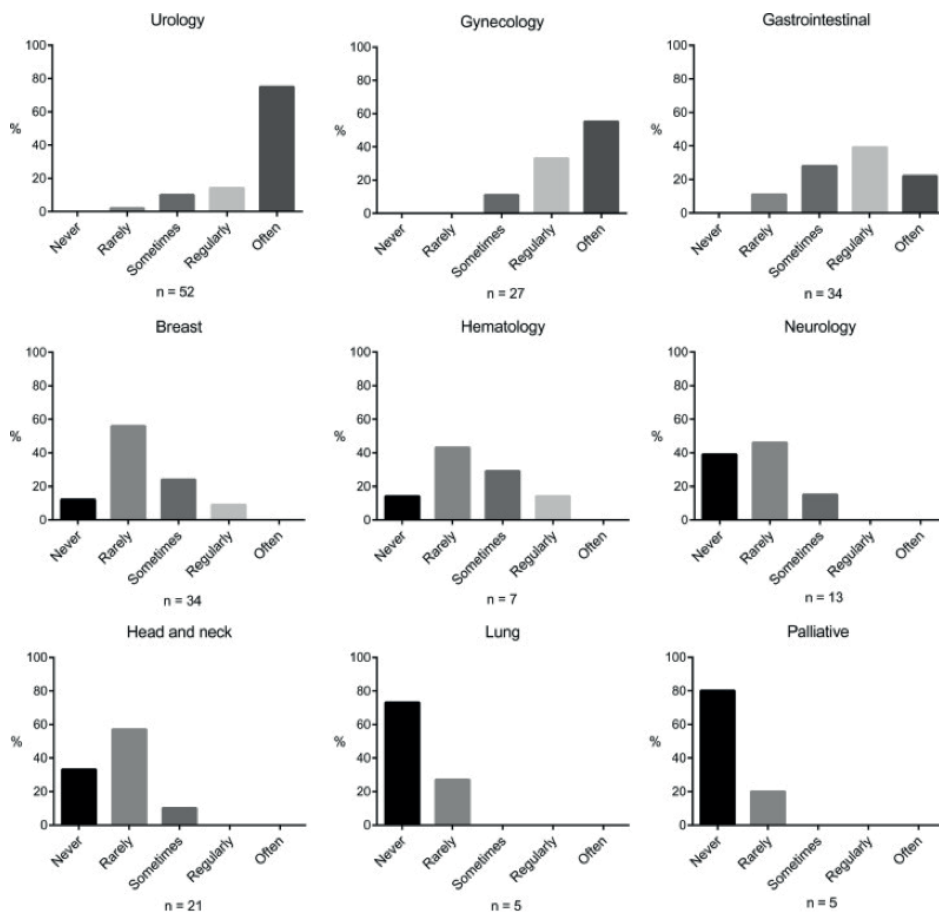
**Table 1.** Demographic characteristics of the respondents (n = 119)

	<i>n (%)</i>
Age (years)	119 (100)
Median 47 years (range 26-66)	
m	
Mean 46.5 years (SD 8.9)	
Gender	
Male	58 (48.7)
Female	61 (51.3)
Function	
Radiation oncologist	116 (97.5)
Resident	3 (2.5)
Radiotherapy experience (years)	
<1	2 (1.7)
1–2	2 (1.7)
3–5	4 (3.4)
6–10	23 (19.3)
11–15	25 (21)
>15	63 (52.9)
Hospital type	
University hospital	60 (50.4)
District general teaching hospital	27 (22.7)
District general hospital	22 (18.5)
Categorical cancer hospital	4 (3.4)
University & district general hospital	3 (2.6)
Independent consultant	1 (0.8)
Not available	2 (1.7)

SD = standard deviation.

## Practice Patterns

Data about practice attitudes regarding sexual function were separated according to area of specialization. Each radiation oncologist was able to provide answers for two areas of specialization and answer the questions for each type of patient. The results to the question “How often do you discuss sexual functioning of the patient?” are featured in Figure 2.



**Fig. 2.** Results to the question “How often do you discuss sexual functioning of the patient?,” allocated for type of cancer.

According to the radiation oncologists involved with care for urology patients ( $n = 59$ ), information about the risk for ED after prostatic RT is given regularly (16.9%) and often (81.3%). The majority declared to inform patients about the use of phosphodiesterase 5-inhibitors regularly (49.2%) and often (40.7%). A few radiation oncologists stated to rarely or never inform patients about erection medication (10.2%). Participants involved with gynecology patients ( $n = 27$ ) gave information about sexual function after RT for cervical cancer rarely ( $n = 4$ , 14.8%) and regularly plus often ( $n = 23$ , 85.2%). Physicians involved with breast cancer patients ( $n = 48$ ) provided information about sexuality in respect to breast radiation never (12.5%), rarely (50%), regularly (18.8%), and often (18.8%).

During conversations about sexual function, the partner was present in half of the cases ( $n = 32$ , 28.8%), more than half of the cases ( $n = 37$ , 33.3%) or almost always ( $n = 38$ , 34.2%). As for the question “How long does it take before treatment adverse effects to sexual function start to decrease?” 62.7% of the respondents ( $n = 69$ ) stated from experience that adverse

effects from RT on sexual function remain forever. Forty-one responders estimated that sexual adverse effects remain for about 3–24 months (37.3%). The majority believed that women who underwent RT for cervical cancer often (82.5%,  $n = 94$ ), regularly (14%,  $n = 16$ ) and sometimes (3.5%,  $n = 4$ ) experience sexual problems, after RT for breast cancer it was believed that women experience problems often (7%,  $n = 8$ ), regularly (38.3%,  $n = 44$ ), sometimes (36.5%,  $n = 42$ ) and never/rarely (18.3%,  $n = 21$ ).

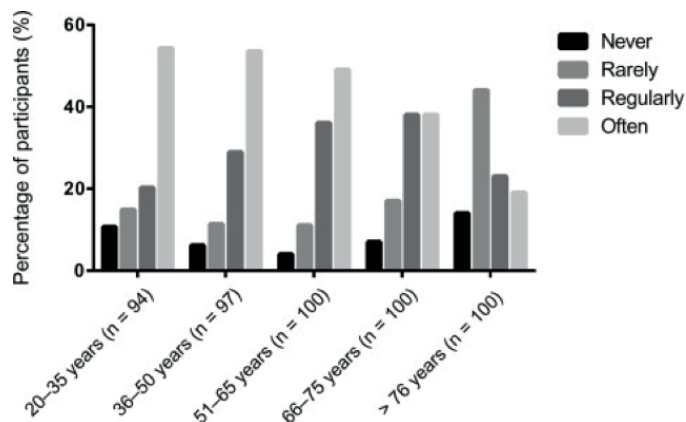
### Responsibility and Referring

Evaluation of treatment-induced SD is the responsibility of the radiation oncologist according to the majority of the respondents ( $n = 87$ , 75%). Remaining respondents considered neutral ( $n = 22$ , 19%) or disagreed having responsibility ( $n = 7$ , 6%). In the following question regarding responsibility of other health care providers (with a multiple answer possibility), a third of the respondents pointed at the referring specialist (e.g., the surgeon, urologist, gynecologist or oncologist) regarding responsibility for discussing SD ( $n = 40$ , 33.6%). A fifth considered the general practitioner responsible ( $n = 25$ , 21%). The primary responsibility of sexual counseling was separately analyzed among all pelvic radiation oncologists ( $n = 65$ , 54.6%), consisting of all radiation oncologists with urology and gynecology as their primary specialism. In this pelvic radiation group, the referring specialist ( $n = 19$ , 29.2%) and general practitioner ( $n = 9$ , 13.8%) were also felt to be responsible for addressing sexual functioning. Sixteen percent of respondents stated that the patient has its own responsibility to initiate discussion on SD.

To the question regarding patient referral in case of SD, 75.9% ( $n = 88$ ) confirmed to have the possibility of referring their patients to an expert on this topic, 24.1% of the radiation oncologists ( $n = 28$ ) was not familiar where to refer patients. The majority of the respondents indicated to be in need of a list with qualified sexual health care providers for referral ( $n = 84$ , 72.4%).

### Barriers

The respondents were given a list of possible barriers for discussing SF, in order for them to indicate to which extent they agreed (Table 2). Radiation oncologists mentioned “patient is too ill” to discuss sexual issues as a major barrier (36.2%). The second barrier, to which 32.4% agreed, was “no angle or reason for asking.” Other barriers were “advanced age of the patient” (27%), “culture/religion” (26.1%), “language/ethnicity” (24.5%), “sexuality is not a patient’s concern” (23.9%), “patient doesn’t bring up the subject” (20%), “lack of training” (19.3%), and “patient is not ready to discuss sexual functioning” (13.1%). The barriers that did not keep radiation oncologists from sexual counseling were all barriers regarding gender, “it’s someone else’s task” (2.6%), “age difference between you and the patient” (3.5%), “afraid to offend the patient” (3.5%), and embarrassment (5.3%). The results to the question concerning the provision of information about treatment-related SD in regard to the age of a patient are displayed in Figure 3.



**Fig. 3.** How often do you discuss sexual concerns with patients in the following age categories?

**Table 2.** Barriers to sexual counseling; sorted from most agreed to least agreed

	Agree	Partly agree/partly disagree	Disagree
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Patient is too ill	41 (36.2)	36 (31.9)	36 (31.9)
No angle or reason for asking	37 (32.4)	21 (18.4)	56 (49.2)
Advanced age of the patient	31 (27.0)	38 (33.0)	46 (40.0)
Culture/religion	30 (26.1)	32 (27.8)	53 (46.1)
Language/ethnicity	28 (24.5)	33 (29.0)	53 (46.5)
Sexuality is not a patient's concern	27 (23.9)	32 (28.3)	54 (47.8)
Patient doesn't bring up the subject	23 (20.0)	19 (16.5)	73 (63.5)
Lack of training	22 (19.3)	35 (30.7)	57 (50.0)
Patient is not ready to discuss sexual functioning	15 (13.1)	39 (33.9)	61 (53.0)
Presence of a third party	13 (11.3)	36 (31.3)	66 (57.4)
Lack of time	13 (11.3)	21 (18.3)	81 (70.4)
Sexuality is a private matter	12 (10.5)	15 (13.2)	87 (76.3)
Lack of knowledge	10 (8.8)	31 (27.2)	73 (64.0)
I feel uncomfortable	9 (7.9)	15 (13.2)	90 (78.9)
Embarrassment	6 (5.3)	14 (12.3)	94 (82.4)
Afraid to offend the patient	4 (3.5)	15 (13)	96 (83.3)
Age difference between you and patient	4 (3.5)	6 (5.2)	105 (91.3)
It's someone else's task	3 (2.6)	24 (20.9)	88 (76.5)
Patient is the opposite gender	2 (1.7)	5 (4.3)	108 (93.9)
Patient is the same gender	-	3 (2.6)	112 (97.4)

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

## Knowledge and Training

To the question regarding knowledge, the majority of radiation oncologists stated to possess some knowledge concerning SD ( $n = 87$ , 67.2%), a quarter of all respondents stated to have sufficient knowledge on SD ( $n = 29$ , 25%) and the remaining respondents stated to have not much knowledge on SD ( $n = 9$ , 7.8%). Radiation oncologists under the age of 47, possessed less knowledge of SD in comparison to respondents of 47 years and older ( $P = 0.046$ ). Gender did not influence the knowledge of SD ( $P = 0.513$ ).

Of all responding radiation oncologists, 44.4% indicated to be in need of additional training regarding discussing sexuality with their patients ( $n = 50$ ). Female respondents more often wished additional training than their male colleagues (55% vs. 33.9%,  $P = 0.023$ ). Age (<47 vs  $\geq 47$  years) did not influence the wish for training (48.3% vs. 41.1%,  $P = 0.432$ ). Almost all respondents agreed that sexual counseling should be a regular component of the radiation oncology residency ( $n = 110$ , 94%).

## DISCUSSION

Key findings of this study are that radiation oncologists routinely discuss sexuality with their urology and gynecology patients, but not so consistently with their gastrointestinal-, breast-, and other cancer patients. The majority of radiation oncologists considered counseling on sexual functioning as part of their job, a third also pointed at the referring specialist as well as a fifth indicated that to be a responsibility of the general practitioner. More than half of the radiation oncologists indicated that radiation effects on sexual function usually persist forever. The majority of radiation oncologists stated to have some knowledge on treatment-related SD. Young radiation oncologists had less knowledge of the topic; illustrating experience might play a role in counseling. An important finding was that 44% of the respondents indicated that they would benefit from additional training regarding sexual counseling in radiation practice; female physicians indicated this wish more often than male physicians. Almost all respondents agreed that training in sexual counseling should be a regular part of RT residency. Barriers for sexual counseling included patient is too ill, no angle or reason for asking, advanced age, and culture or religion.

### Comparison with Literature

To our knowledge, this survey was the first evaluation in Europe of radiation oncologists' attitudes and practice patterns regarding sexual health. In China, a similar evaluation was performed among radiation oncologists, also evaluating attitudes and behavior toward sexual issues of patients who received RT [25]. In line with our results, the radiation oncologists felt responsible for addressing the issue, nonetheless, dissimilar to our results they hardly addressed the issue spontaneously but only when the patient explicitly consulted them on this issue. The

majority of Chinese radiation oncologists expressed the need for training to enable them to provide guidance to patients, in the present study this was less than fifty percent. Wang et al. [25] found 41.7% of their surveyed radiation oncologists to be uncomfortable discussing sexual functioning with a patient, compared with 20% of the Dutch radiation oncologists, illustrating that the East Asian attitude regarding sexuality might differ from the non-Asian perspective.

In the United Kingdom, a survey among specialist gynecologic oncology nurses and an evaluation of the content of patient brochures showed a prominent lack of psychosexual content for example regarding vaginal dilatation in both clinical counseling and written materials [33]. Vaginal dilatation after pelvic radiation is recommended in order to maintain patency of the vagina. Although there is no reliable evidence on preventing stenosis, several reports suggest that women who dilate their vagina after RT reported and measured less stenosis [34]. Furthermore, a psycho-educational intervention is demonstrated to increase compliance of the use of vaginal dilators compared with supplying information only [35]. As for Faithfull et al. their “information after pelvic radiation” survey, physicians rarely provided patient education in relation to sexual health advice and vaginal dilatation [33]. Patient education was considered a nursing or radiographer role; however, the physician was thought to be the one to evaluate on a patient’s compliance regarding any intervention. Noteworthy, it appeared information was solely provided for gynecology patients, even though pelvic radiation therapy is also frequently used for the treatment of women with bladder, rectal and anal tumors.

The discrepancy between doctors’ assumptions and the actual experienced complaints after receiving pelvic RT have also been emphasized in other reports, showing underreport of vaginal discomfort and underestimation of ED by physicians. In the United Kingdom, RT follow-up consultations were observed in order to determine the clinical assessment of treatment-induced female sexual difficulties [26]. Results showed acknowledgment by both patient and physician in the challenge of discussing sexual concerns. Barriers included the different priorities during consultations; like attention for possible recurrence of disease, lack of time, lack of expertise and lack of adequate referral pathways.

Vistad et al. compared physician-assessed morbidity (including vaginal discomfort) with reported symptoms from patients treated with RT for cervical cancer. Patient morbidity scores correlated poorly with data reported by physicians, confirming underreporting and underestimation of intestinal and bladder morbidity [24]. Vaginal discomfort was not compared with physician data; at follow-up only two-thirds of the patients were examined for vaginal symptoms, indicating the physician did not actively counsel at all.

Showalter et al. surveyed the estimation of 926 radiation oncologists on how often RT affected recovery of ED after radical prostatectomy. Significantly less radiation oncologists (47%) predicted a “major/total detrimental effect” to erectile function following RT in comparison with urologists (69%) [36]. With respect to patient-reported outcomes regarding RT for prostate cancer, the number of patients reporting inability to achieve an erection sufficient



for intercourse after 2 (60.8%), 5 (71.9%), and 15 years (93.9%) illustrates the underestimation of the radiation oncologists [37].

Clearly, the main barriers toward sexual counseling detected in the current survey can be opposed. The primary reason for not discussing sexual health “the patient is too ill” should be questioned, considering the body of evidence reporting on the importance of sexual function to the quality of life of patients with all sorts of cancer patients being in early as well as advanced stages. The second barrier, “no angle or reason for asking,” can easily be tackled by the provision of practical training on how to address the subject. By providing informed consent and mentioning possible treatment-related SD, as well as additionally notifying that the patient should address any concerns, the key component of sexual health care has already been performed. The third barrier, advanced age of the patient, was also found in a recent survey among a group of surgical oncologists [31]. Apparently, physicians seem to consider that elderly patients are not sexually active anymore and the subject is consequently not relevant to discuss. This assumption might be rather incorrect; according to a study on the prevalence of sexual activity among 3005 adults of 57–85 years, a serious percentage of older adults is still sexually active [38], making this barrier defeasible.

## Limitations

This study has a few limitations. We used a non-validated questionnaire, as there are no validated questionnaires available that assess the provision of sexual counseling by radiation oncologists. In order to explore the aim of the study, specific questions were required regarding sexual function in the face of radiation therapy. For this reason, we developed a particular questionnaire investigating the aims and influencing factors instead of using a validated, more general instrument. Nevertheless, the questionnaire was based on other surveys of the research group, which successfully assessed the provision of sexual counseling by several (oncology) health care providers [28–32]. As for an approximation toward validation, an extensive pilot study was performed and the instrument was adjusted because of the comments. Test–retest reproducibility of the questionnaire was not tested due to the anonymous design; therefore, nothing can be said about the reproducibility of the questionnaire. Another important limitation, which may have resulted in over- or underestimation, is that physician responses were self-reported. Attempts were made to reduce this bias by collecting the survey results anonymized.

The subdivisions by area of specialization resulted in small numbers of radiation oncologists in each group. For this reason, it was not possible to reflect on the relationship between frequency of counseling sexual function and demographic characteristics of the respondents. At the same time, because of the subdivisions we were able to produce a detailed insight in patient groups who might lack attention for SD following RT. Only three residents responded to the survey, which made it impossible to calculate differences in results between residents and radiation oncologists. Different treatment settings, knowing curative therapy, salvage therapy and palliative radiation, where not in particular assessed in this survey. As a result, nothing can

be concluded about the approach of radiation oncologists toward patients receiving a different type of treatment. The response rate was comparable with that of other postal questionnaires among physicians [39]. Nevertheless, nonrespondents may have different beliefs, attitudes and practice patterns than respondents, this may have caused a nonresponse bias and hence radiation oncologists may perform less or more active counseling for sexual problems after RT in daily practice.

## CONCLUSIONS

Findings suggest that awareness of treatment induced SD is present among radiation oncologists, but responsibility for active counseling was not fully agreed on. Counseling on sexual function is routinely done in case of pelvic radiation therapy, but not consistent in case of gastrointestinal, breast and other cancers. According to the majority of the radiation oncologists, treatment-induced effects on sexual function are lasting forever. Radiation oncologists stated the preference for more detailed education about discussing SD in daily practice, and indicated that education about sexual issues should be a routine component of the residency in radiation oncology. A list for specialized referral regarding patients experiencing treatment-induced SD is requested.

### Implications for Clinical Practice

In order to provide this component of care, radiation oncologists need to have good communication skills, an open and nonjudgmental approach, and knowledge of the potential consequences of radiation therapy on sexuality. Especially for gastrointestinal patients who possibly receive radiation on or close to the pelvic area, awareness should be improved among radiation oncologists. Both standard education within radiation oncology residency as additional education for practicing radiation oncologists are strongly recommended. Radiation oncologists who have the intention to integrate sexual health in their practice and would like to make use of a structured framework, could for example counsel with the widely used Permission (P), limited information (LI), specific suggestions (SS), and intensive therapy (IT) (PLISSIT) model [40]. Guidelines and standard operating procedures for radiation treatment should implement possible sexual side effects and the importance of addressing them as a part of informed consent and follow-up. Within the oncology team, clear appointments should be made regarding responsibility for addressing sexual issues with every patient before and during treatment. A list with specialized sexual health care providers should become available for referral of patients in need of specialized advice.

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# Chapter 5

## *Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges*

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## INTRODUCTION

It is widely known that sexual dysfunction is a common side effect of oncological disease. All cancer therapies, including chemo-, hormonal- and immunotherapy, radiation and surgery can impair the sexual function. The prevalence of sexual side effects following therapy varies, depending on cancer and therapy type, but may even rise to 100% after treatment of genital cancers [1–5]. Cancer patients often face sexual symptoms from the start of treatment and these are likely to continue or even increase in the long term [6]. The consequences of cancer treatment can influence all aspects of sexuality, including desire, satisfaction and functioning. Sexuality is considered an extremely important quality-of-life concern by cancer survivors [7–9]. Despite reporting concerns regarding their sexual function, patients are frequently not informed about how treatment may affect their sexual function [1, 10, 11].

Given the high prevalence of sexual dysfunction and the complexity of the problems, an integrative approach to potential sexual problems is needed. Literature reveals a mismatch in expectations between the patient and healthcare providers regarding communication about sexuality [12–14]. Patients reported unmet needs regarding discussing sexuality with their health care providers. While some patients wish to discuss this topic, they feel health care providers do not provide an opportunity to talk about sexual function or even ignore their sexual needs [5, 11, 12, 15–17]. On the other hand, not all healthcare professionals consider it their task to discuss the subject [18]. Moreover, they face several other barriers, such as uncomfortable feelings, insufficient knowledge, lack of training, lack of time and over involvement in aspects of patients' personal lives. Oncology care providers do, however, consider sexual function to be an important topic [18–21]. During cancer treatment, patients are treated by different professionals within a multidisciplinary team. It is not always clear which member of the team is responsible for addressing sexual function. Studies among different Dutch oncology care providers revealed that members of the oncology team, like radiation oncologists, oncology nurses and oncology surgeons, see some role for themselves in sexual function counselling, but all point to the medical oncologist to bring up the subject [19–21].

Consequently, it is important to identify how medical oncologists report their own role in sexual counselling. An understanding of how medical oncologists acquire knowledge about sexual function counselling, how they apply sexual function counselling in practice, and which barriers they may encounter when bringing up the subject is needed to optimise management around sexual care for oncology patients. The aim of this study is to explore the attitude, practice patterns and education needs of medical oncologists regarding sexual function counselling.

# METHODS

## Study Design

A questionnaire was used to collect data in a cross-sectional survey. The questionnaire was sent to 433 members of the NVMO (Dutch Society of Medical Oncology). The total number was 440, but 7 members living and practising oncology abroad were excluded (most of them from the Netherlands Antilles). Members of the NVMO include both medical oncologists and oncology differentiating residents. Our sampling strategy aimed to represent area of expertise, employment setting, level of education, years of oncology experience, type of hospital, age and gender.

## *Survey Administration*

The questionnaires and reminders were sent in 2014. Non-responders received a reminder twice. The questionnaires were sent by post and included a stamped, addressed envelope. Reason for using a postal survey was to obtain the highest possible response rate. In studies with participants between 30 and 60 years old or older, the highest response rate was seen in postal surveys [22–24]. We expected the average age of our respondents to be older than 30 years. Furthermore, we wanted to prevent younger, male, avid Internet users and those with greater technological interest to be over-represented in the survey [22, 25].

## Instrument Design and Development

The questionnaire consisted of 38 questions. It contained questions on demographics, frequency of discussing sexual function, the patient's view about the responsibility for discussing sexual function, barriers faced when discussing sexual function, self-reported knowledge about sexual function after cancer treatment and the need for additional training. The questionnaire was developed by the authors based on several items found in relevant literature and on previously conducted sexuality questionnaire studies among health care professionals. The latter was derived from our research group and concerned questions about practice patterns, knowledge, barriers and responsibility regarding treatment-related sexual function [19–21]. The content of the questionnaire was pilot-tested by four oncologists from the area of Leiden, the Netherlands. A small pilot panel was chosen because of the limited number of oncologists in the Netherlands; the members of the pilot panel were not invited for the survey. The pilot panel reviewed the questionnaire with regard to relevance, integrity, structure, layout and spelling.

## Analysis

Data analysis was performed using SPSS (Release 23; SPSS Inc.). Demographic information and answers to the survey were analysed using descriptive statistics. Equality of proportions between groups was tested with Pearson's chi-square test; for ordinal variables, the Armitage's trend test was applied. Continuous variables were compared using Student's *t* test. Age groups were divided into two groups: under 47 years and 47 years and older (according to median age

of 47 years). The group was divided into two according to experience: up to 10 years and more than 10 years of experience. Two-sided  $P$  values  $< .05$  were considered statistically significant.

## **Ethical Consideration**

The study was formally approved by the scientific committee of the Department of Urology of the LUMC. In the Netherlands, research that does not involve patients or interventions is not subject to permission from ethical boards. In previous research using similar types of questionnaires, the Medical Ethics Committee was consulted by our research group. As the study did not concern 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.

## **RESULTS**

### **Participants**

The survey was distributed among 433 medical oncologists; 209 of them responded (initial response rate 48.3%). Of these 209 responders, nine were returned to sender, 26 oncologists reported they had retired and 6 were not medical oncologists. A notification of refusal was received from 48, 39.3% ( $n=35$ ) of whom refused due to lack of time. Of 392 eligible participants, 120 completed questionnaires were returned and included for analysis, resulting in a final response rate of 30.6%.

The mean age of the respondents was 47 years (range 30–64) and half of them ( $n=56$ , 52.5%) were male. The male respondents were significantly older than female respondents ( $p<0.001$ ). The majority ( $n=72$ , 61%) reported  $>5$  years of experience working in the field of oncology. Areas of expertise and clinical settings are presented in Table 1.

### **Addressing Sexuality in Medical Practice**

The medical oncologists participating in this survey estimated that 70.6% (SD 17.21, range 20–100%) of their patients may experience sexual changes as a result of cancer treatment. Most respondents ( $n=97$ , 81.5%) reported discussing sexual function in fewer than 50% of their patients. There was no significant difference in frequency of discussing sexual function between male and female specialists, years of experience or age of the oncologist (resp.  $p=0.503$ ,  $p=0.471$ ,  $p=0.178$ ). Three-quarters ( $n=90$ ) of the responding oncologists stated that they discussed sexual function in fewer than half of the cases during the informed consent conversation before the start of treatment. Findings are summarized in Table 2. The main topics being discussed were decreased libido ( $n=65$ , 72.2%), menopausal symptoms ( $n=63$ , 70%), insufficient lubrication ( $n=60$ , 66.7%) and pain during intercourse ( $n=48$ , 53.3%) in women. Erectile dysfunction ( $n=74$ , 82.2%) and decreased libido ( $n=73$ , 81.1%) were frequently discussed with male patients.

**Table 1.** Participant characteristics

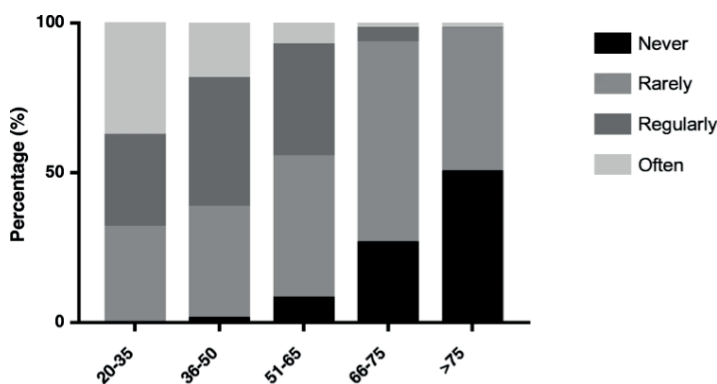
<b>Oncologists (n=120)</b>	
Median age in years (range)	47 (30-64)
Age of male respondents (years)	50.6 (SD 10)
Age of female respondents (years)	41.9 (SD 8.9)
<b>Gender</b>	<b>n (%)</b>
Male	56 (46.7)
Female	63 (52.5)
Unknown	1 (0.8)
<b>Function</b>	
Oncologist	101 (84.2)
Oncology resident	19 (15.8)
<b>Area of expertise<sup>a</sup></b>	
Breast	88 (73.3)
Colorectal	79 (65.8)
Palliative care	57 (47.5)
Gynecology	53 (44.2)
Nephrology and urology	53 (44.2)
Hematology	37 (30.8)
Lymphoma	32 (26.7)
Head and neck	14 (11.7)
Neuroendocrine	14 (11.7)
Melanoma	8 (6.7)
Sarcomas	8 (6.7)
Lung	3 (2.5)
<b>Type of practice</b>	
District general hospital	47 (39.2)
University hospital	40 (33.3)
District general teaching hospital	27 (22.5)
Cancer institute	3 (2.5)
Both university and district	2 (1.7)
Unknown	1 (0.8)
<b>Oncology experience</b>	
< 1 year	0
1–2 years	19 (15.8)
3–5 years	27 (22.5)
6–10 years	13 (10.8)
11–15 years	19 (15.8)
>15 years	40 (33.3)
Unknown	2 (1.7)

<sup>a</sup> Most respondents reported multiple areas of expertise.

**Table 2.** Discussing sexual function in daily practice

	Total respondents	Never/ rarely <i>n</i> (%)	In less than half of the cases <i>n</i> (%)	In half of the cases <i>n</i> (%)	In more than half of the cases <i>n</i> (%)	Often/ always <i>n</i> (%)
How often do you discuss sexual function with your patients?	118	43 (36.1)	54 (45.4)	16 (13.4)	3 (2.5)	2 (2.5)
How often do you inform your patients about the possible effects on sexual health during an informed-consent conversation?	120	37 (30.8)	53 (44.2)	14 (11.7)	10 (8.3)	6 (5)
During follow-up, how often do you discuss sexual health with patients?	90	37 (40.7)	45 (49.5)	3 (3.3)	5 (5.5)	0

Among oncologists who did discuss sexual function, 91.4% ( $n=83$ ) reported addressing this subject when treatment had a curative intent. This declined to 62.4% ( $n=57$ ) when the treatment had a life-prolonging intent and to 33.3% ( $n=30$ ) in cases of palliative treatment. The oncologists discussed sexuality more often with younger patients. Sixty-eight per cent ( $n=61$ ) of the respondents discussed sexuality regularly/always with patients between 20 and 35 years of age; this percentage declined to 2.2% ( $n=2$ ) in patients older than 75 years. All age groups are represented in Fig. 1.



**Fig 1.** How often do you discuss sexuality with in the following age groups (years)?

## Responsibility and Barriers

Of all oncologists, a large majority of 75.8% ( $n=91$ ) stated they felt responsible for discussing sexual function with their patients. A similar percentage (75%,  $n=90$ ) indicated they considered the oncology nurse also to be responsible and half of the respondents ( $n=61$ ) thought the patient was responsible for initiating the subject. Responsibility allocated to possible health care providers and the patient or partner is displayed in Table 3. A minority ( $n=14$ , 12.8%) of respondents stated there was an agreement defining responsibility for discussing sexual function within their multidisciplinary team.

**Table 3.** Responsibility for addressing sexual health according to the oncologists

Who is responsible for addressing sexual function? (multiple answers possible)	<i>n</i> (%)
Oncologist	91 (75.8)
Oncology nurse	90 (75)
Patient	61 (50.8)
Partner of patient	28 (23.3)
General practitioner	28 (23.3)
Psychologist	14 (11.7)
Social worker	6 (5)
Physiotherapist	1 (0.8)

According to the medical oncologists, the major barriers for discussing sexual function were ‘lack of time’ ( $n = 64$ , 56.1%), ‘advanced age of the patient’ ( $n = 57$ , 50.4%), ‘lack of training’ ( $n = 51$ , 49.5%) and ‘patient is too ill’ ( $n = 51$ , 49.5%). Less-experienced oncologists ( $\leq 10$  years of practice) stated lack of time as a reason more often than their more experienced colleagues ( $p = 0.006$ ). Other barriers to avoid having to address sexual function are listed in Table 4.

**Table 4.** List of boundaries for discussing sexual function

Reasons for avoiding discussion of sexual health	Total respondents*	Agree <sup>a</sup> <i>n</i> (%)	Partly agree/ disagree <i>n</i> (%)	Disagree <sup>a</sup> <i>n</i> (%)
Lack of time	114	64 (56.1)	27 (23.7)	23 (20.2)
Advanced age of the patient	113	57 (50.4)	26 (23)	30 (26.5)
Lack of training	113	51 (49.5)	35 (31.0)	27 (23.9)
Patient is too ill	114	51 (44.6)	35 (30.7)	28 (24.6)
No angle of motive for asking	114	45 (39.5)	39 (34.2)	30 (26.3)
Lack of knowledge	114	41 (36)	40 (35.1)	33 (28.9)
Patient doesn't bring up the subject	114	38 (33.3)	32 (28.1)	44 (38.6)
Culture/religion	114	27 (23.7)	34 (29.8)	53 (52.6)
Language/ethnicity	113	27 (23.9)	28 (24.8)	58 (51.3)
Surviving is more important	115	26 (23.1)	37 (32.7)	50 (44.2)
I feel uncomfortable	115	26 (22.8)	37 (32.5)	51 (44.7)
Sexuality is not a matter of life or death	114	25 (21.9)	37 (32.5)	52 (45.7)
Not relevant for all types of cancer	114	25 (21.9)	23 (20.2)	66 (57.9)
Presence of a third party	111	24 (21.6)	26 (23.4)	61 (54.9)
Patient is not ready for discussing sexual health	102	22 (19.7)	34 (30.4)	46 (50)
Sexuality is a private matter	131	21 (18.6)	53 (31)	57 (50.5)
Embarrassment	114	20 (17.6)	32 (28.1)	62 (62.3)
It is someone else's task	113	17 (15)	27 (23.9)	69 (61)
No trust in treatment for sexual dysfunction	112	13 (11.6)	32 (28.6)	67 (59.8)
Concerned about causing the patient discomfort	114	12 (10.5)	30 (26.3)	72 (63.1)
Sexuality is not a patient's concern	114	11 (9.7)	37 (32.5)	66 (57.9)

**Table 4.** List of boundaries for discussing sexual function (*continued*)

Reasons for avoiding discussion of sexual health	Total respondents*	Agree <sup>a</sup>	Partly agree/ disagree	Disagree <sup>a</sup>
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Age difference between you and patient	114	10 (8.8)	21 (18.4)	83 (72.8)
Afraid to offend the patient	114	6 (5.3)	15 (13.2)	93 (81.5)
Patient is the opposite gender	114	4 (3.5)	16 (14)	94 (82.4)
Patient is the same gender	112	0 (0)	7 (6.3)	105 (93.7)
Colleagues think it's inappropriate to discuss sexual issues with patients	113	0 (0)	11 (9.7)	102 (90.3)

\*Not all respondents answered each question

## Knowledge, Education and Training Needs

A small percentage of the respondents ( $n=14$ , 15.4%) stated they had sufficient knowledge to be able to discuss the subject. All other respondents ( $n=77$ , 84.6%) stated having little or no knowledge of the subject. Oncologists with more self-stated knowledge discussed sexual function more often ( $p=0.002$ ). According to 85% ( $n=102$ ), education about sexual function counselling within their oncological training was insufficient. A majority of 72.9% ( $n=86$ ) would like to acquire more training in the counselling of sexual function, regardless of their self-stated knowledge ( $p=0.733$ ). No significant differences were found in training needs between areas of expertise.

## DISCUSSION

The present study provides insight into the practice patterns of Dutch medical oncologists with regard to discussing sexual function. It reveals the origins of several difficulties in discussing sexual function in current clinical practice. Medical oncologists do see sexual function counselling as part of their duty. Nevertheless, they do not routinely counsel sexual function due to several barriers, such as lack of training. A minority informs their patients about potential sexual side effects of planned cancer treatment. Whether oncologists counsel patients is related to the age of the patient, how they view the patient's prognosis and to whether they stated they had more knowledge about sexual function.

The results of this study are in line with other self-reported surveys among oncology health care providers about communication regarding sexual concerns. To our knowledge, this is the first study to describe how medical oncologists see their role in sexual counselling, depicting the actual origin of difficulties in discussing sexual issues in current clinical practice.

According to our data, Dutch oncologists rarely bring up sexual side effects during the informed consent conversation before starting a treatment. Informed consent is seen as a crucial component of medical practice and authenticates patients' autonomy. During informed consent, adverse effects that are common should be discussed [26]. Given the high prevalence and additional burden of sexual dysfunction after cancer treatment, sexual side



effects of treatment should be part of informed consent [1–5, 26]. Lack of knowledge, lack of time and lack of clarity about sexual side effects in current guidelines may result in ambiguity regarding responsibility for discussing sexual side effects [18]. An example of how to enhance communication about sexual side effects during informed consent is the use of an informed consent template, provided by the ASCO, where side effects, including sexual side effects are mentioned [27]. Nevertheless, a form cannot replace direct patient-provider communication but could help the care provider to address the subject.

Since sexual problems can arise during early treatment, but may also arise after treatment and even extend long term, discussing sexual function during the whole cancer care process would seem to be important [6]. However, the current survey revealed that Dutch oncologists do not routinely bring up the subject of sexuality during treatment and follow-up. According to the literature, other members of the multidisciplinary oncological team identified discussing sexual function as a responsibility of the oncologist [19–21]. Members of the multidisciplinary oncological team seem to count on each other to tackle the conversation about sexual health. This highlights the importance of defining responsibilities within the oncology treatment team. According to this survey, only 12.8% of the respondents reported a clearly defined responsibility for addressing sexuality within their team. De Vocht et al. described a Stepped-Skills-model, which could be of help to define responsibilities [18]. In this team-approach-model, there are team members who are ‘spotters’. These spotters, most likely the oncologist, discuss the sexual side effects of treatment, check whether patients need help and refer them where necessary. Other members, most probably the specialized nurses, are called ‘skilled companions’. They have the responsibility to support patients in their sexuality issues. Consequently, these members require training to improve their communication skills and their knowledge. Using such an integrated approach, sexual health may become part of daily clinical practice.

As already highlighted in the ‘Introduction’ section, a mismatch in expectations regarding the discussion of sexual health between patient and providers does exist. The current study reveals some of the reasons why medical oncologists do not bring up sexuality, which may contribute to this mismatch. Of the respondents, almost 60% stated the ‘advanced age of the patient’ as a barrier to discussing sexual function, suggesting respondents may assume elderly patients are not sexually active. This may be an incorrect assumption. A study on the prevalence of sexual activity among 10,000 European adults showed that sexual desire and activity persist through old age, with 53% of the male respondents and 21% of the female respondents between 70 and 80 years of age being sexually active [28].

Another barrier to discussing sexuality mentioned by almost half of the oncologists involved ‘the patient being too ill’. Also, frequency of bringing up sexual health declined when treatment had a palliative intent compared to a curative intent. A study reviewing sexual healthcare for cancer patients receiving palliative care confirmed a lack of sexual health care in this patient group, although the patients and their partners did feel the need for a conversation about the subject. Bringing up the subject of sexuality by a healthcare professional even improved

quality of life and reduced stress of patients and partners [29]. An interdisciplinary approach is required to recognise and manage symptoms in this palliative group.

In accordance with previous investigations, important reasons for the lack of frequency in discussing sexual health were a 'lack of training' and a 'lack of knowledge' [15, 19–21]. These evidently recurrent barriers among different cancer care providers in different countries indicate that there is a role for education and practical training to improve the situation in practice. A pilot study involving 82 oncology providers showed that a brief (30–34 min) targeted sexual health training significantly enhanced the frequency of discussing sexual issues with cancer patients [30]. In Iceland, a sexual health care educational intervention was implemented over a 2-year time period. Over 200 oncology nurses and physicians participated. The study showed that the perceived level of knowledge in providing sexual health care was higher after the intervention [31]. Furthermore, communication tools, using standard patient questionnaires on sexuality resulted in improved communication between the patient and the health care provider regarding sexual function [32]. However, with the increasing pressure on daily practice of physicians and nurses, and taking another major barrier—lack of time—into consideration, we are urged to look for additional ways of providing sexual health care. Possibilities for educating patient and partner regarding sexual function during and after cancer treatment, like e-health, using websites, videos and apps, have to be further investigated and evaluated.

Some limitations need to be considered. As no validated questionnaires were available, a non-validated questionnaire was administered. The use of a self-reported questionnaire may have led to under- or overestimation. Questionnaire-based studies are always subjected to response and selection bias. A sampling error may have occurred due to the low response rate, although this rate was comparable to that found by other questionnaire studies. There may be a difference between the oncologists who responded and those who did not respond to our questionnaire, possibly creating a bias. The fact that a postal survey was used may have resulted in incomplete responses. Internet questionnaires are known to have a higher degree of completeness since the researcher is able to compensate for errors among respondents who for example accidentally pass over a question [24]. The subdivisions by area of specialisation resulted in small numbers of medical oncologists in each group. For this reason, it was not possible to do proper sub-analyses per area. The area of specialisation of the majority of the responding oncologists was breast cancer. The questionnaire may, therefore, have been answered in the context of breast cancer, meaning the patients were slightly younger and were receiving (neo) adjuvant chemotherapy or hormonal therapy, with the accompanying effects on sexual functioning. A larger study among medical oncologists from different countries might be useful in defining differences between areas of specialisation.

The results of this study may improve the awareness of health care professionals in cancer treatment, especially medical oncologists, about the need to define the place of sexual health care in the course of the disease trajectory, to discuss if a specific team member is responsible for initiating the subject and, if necessary, provide additional training.

## CONCLUSION

The current study reveals that medical oncologists do not routinely counsel patients concerning sexual function being confronted by several barriers, although they do see this as part of their role. Patients' prognosis, patients' age and how knowledgeable the oncologist is about sexual function influence the frequency of counselling. Our findings indicate that there is a role for education and practical training for improving sexual health care in the oncology practice.

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# Chapter 6

## *Omissions in Urology Residency Training Regarding Sexual Dysfunction Subsequent to Prostate Cancer Treatment: Identifying a Need*

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## INTRODUCTION

Prostate cancer is the most commonly occurring male urological cancer. In 2012, about 1.1 million cases were diagnosed worldwide.<sup>1</sup> Accordingly, prostate cancer's diagnostics, treatment, and follow-up are part of every urologist's training. Sexual dysfunction, usually resulting from erectile dysfunction (ED), is one of the most prevalent consequences of prostate cancer treatment.<sup>2</sup> Other sexual side effects include decreased sexual desire, ejaculation disorders, and orgasm impairment.<sup>3</sup> After radical prostatectomy (RP), the rate of ED varies from 25% to 90%, depending on pre-existing erectile function, age, definition of ED, preservation of neurovascular bundles, the surgeon's experience, and surgical technique.<sup>2, 4, 5</sup> Up to 64% of patients experience ED after external beam radiation therapy, and about 50% of men report ED following brachytherapy.<sup>2, 6</sup> Furthermore, the erectile function is affected in up to 85% of patients receiving androgen deprivation therapy.<sup>7</sup>

Experiencing sexual problems, which is in most cases ED, can severely affect quality of life.<sup>8</sup> Consequently, it is crucial that patients are well informed about the possibility of developing sexual dysfunction as a part of informed consent and about treatment options for ED.<sup>9</sup> Training in the counseling of sexual issues and the treatment of sexual dysfunction frequently does not form part of the medical school curriculum,<sup>10</sup> implying that few physicians receive education about sexual function and practical skills to adequately perform sexual counseling before starting urology residency.<sup>11</sup> Due to the lack of fundamental training, urology residents may not feel well equipped or sufficiently confident to discuss these problems. Considering urologists are consulted by numerous prostate cancer patients during their careers, it is highly relevant that residents obtain knowledge and skills and are comfortable about addressing sexual concerns. The aim of this study was to assess urology residents' current knowledge and practice in and barriers to discussing sexual dysfunction, whether formal training in the counseling of prostate cancer-related sexual dysfunction is provided, and the potential need for additional training.

## MATERIALS AND METHODS

Questionnaires were distributed to Dutch urology residents visiting a national training course halfway through the academic year in June 2015, to perform a cross-sectional survey. The study sample targeted all third to sixth year urology residents in the Netherlands (n = 101), excluding first and second year residents as they perform general surgery rotations and do not yet counsel prostate cancer patients. Residents who were not able to attend the course have not been approached. Questionnaires were completed individually and anonymously at the beginning of a lecture, after which they were returned in the envelope provided.

The instrument was designed by the authors, as no validated questionnaire for assessing the study objectives is available. Questions were based on the study aim and previous questionnaires investigating the provision of sexual health care by oncology care providers.<sup>12, 13, 14</sup> A pilot study was performed by three senior medical interns, checking the length, layout, linguistic flaws, comprehensiveness of questions, and responses. On the basis of their comments, questions were removed and small modifications were made. The final questionnaire consisted of 25 items assessing the following topics:

- demographic details
- previously received educational training in sexual dysfunction
- sufficiency of current education on sexual dysfunction and potential training need
- competence in discussing sexual function with prostate cancer patients
- practice in addressing and treating sexual function. Familiarity with referral options, awareness of responsibility for addressing sexuality within the treatment team, and availability of information material
- possible barriers that prevent residents from discussing sexuality
- factors that would assist in implementing sexual counseling in daily practice

Quantitative data were analyzed using SPSS 20 (Chicago, IL). Frequency analysis and descriptive statistics were used to assess numerical values. Bivariate associations between demographic information and categorical data were calculated using Pearson's chi-square procedure and means in different groups using independent sample *t* test. Two-sided *P* values <.05 were considered statistically significant.

## RESULTS

### Survey Population

All residents who attended the course (*n* = 87) agreed to participate in the survey, resulting in a response rate of 100%. Currently, the Netherlands comprises a total of 101 third to sixth year urology residents; thus, 86.1% of all residents were included in the sample. Demographic characteristics, residency year, and clinical settings are presented in Table 1.

### Knowledge and Training

Of all participating residents, 58.6% had never received training or education about addressing sexuality during their career (*n* = 51); also, a significant percentage of fifth and sixth year residents had never attended a sexuality training (Fig. 1). Of the participants who had received training or education, 17 residents stated they had attended a lecture concerning this subject, 8 respondents had undertaken self-study, 6 had participated in a workshop, 8 had attended an educational training within their hospital, and 5 declared they had visited reference evenings or congresses that addressed sexuality. When it comes to knowledge, 45 residents reported possessing sufficient knowledge (51.7%), 39 had limited knowledge (44.8%), and 3 had little knowledge (3.5%). Table 2 shows the level of knowledge in relation to other reported factors.

**Table 1.** Demographic characteristics (n = 87)

	<i>n (%)</i>
<b>Gender</b>	
Male	39 (44.8)
Female	48 (55.2)
<b>Age (years)</b>	
Median 32.0 (range 28-38)	87 (100.0)
Mean 32.7	
<b>Year of residence</b>	
3 <sup>rd</sup> year	17 (19.5)
4 <sup>th</sup> year	23 (26.4)
5 <sup>th</sup> year	25 (28.7)
6 <sup>th</sup> year	21 (24.1)
NA	1 (1.1)
<b>Clinical setting</b>	
University hospital	46 (52.9)
District general teaching hospital	35 (40.2)
District general hospital	5 (5.7)
Cancer institute	1 (1.1)

NA: Not available

**Table 2.** Association between level of knowledge and characteristics of residents (n = 87)

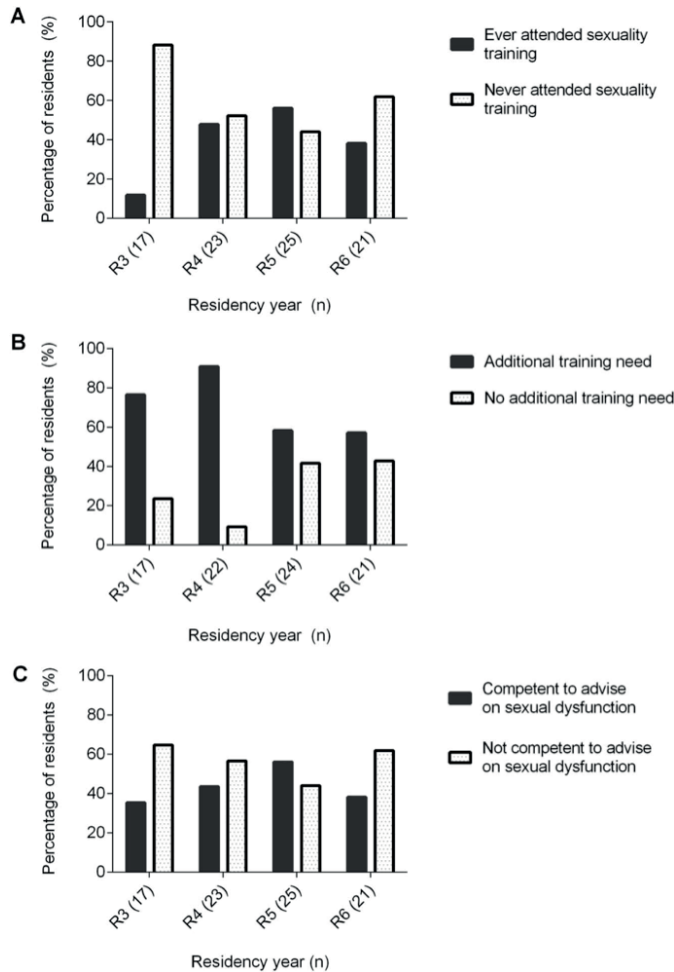
	<b>Sufficient knowledge</b>	<b>Limited and little knowledge*</b>	
	<i>n (%)</i>	<i>n (%)</i>	<i>P value</i> †
Male	25 (64.1)	14 (35.9)	0.037
Female	20 (41.7)	28 (58.3)	
Third and fourth year of residency	16 (40)	24 (60)	0.053
Fifth and sixth year of residency	28 (60.9)	18 (39.2)	
28 to 32-year-old residents	23 (52.3)	21 (47.7)	NS
33 to 38-year-old residents	22 (51.2)	21 (48.8)	
Attended a sexuality training	24 (66.7)	12 (33.3)	0.019
Never attended a sexuality training	21 (41.2)	30 (58.8)	
Feels competent to advise on treatment of sexual dysfunction	27 (69.2)	12 (30.8)	0.003
Does not feel competent to advise on treatment of sexual dysfunction	18 (37.5)	30 (62.5)	
Preference for enhancing knowledge	24 (40.7)	35 (59.3)	0.006
No need to enhance knowledge	19 (73.1)	7 (26.9)	

NS: Not significant

\* Limited and little knowledge taken together, as the expected measure of limited knowledge (n = 3), was too low for adequate computing.

† Chi-square procedure.

More than half of the residents agreed that poor (54.8%,  $n = 46$ ) and below-average (3.6%,  $n = 3$ ) attention is paid to sexual health issues during their current urology residency. Sixty-nine percent ( $n = 59$ ) would like to enhance their knowledge with regard to discussing sexuality with patients and treatment of sexual dysfunction, including fifth and sixth year residents who indicated a preference for additional training (Fig. 1).



**Fig. 1.** Attendance of sexual dysfunction training in the past (A), additional training need (B), and self-reported competence in advising on sexual dysfunction (C) presented by residency year (R3–R6).

## Competence in Discussing Sexuality

The statement “I feel competent to address sexual side effects” was answered affirmatively by 50.6% of the residents, and a majority of 78.2% felt sufficiently competent to inquire about sexual problems. Gender did not influence the competence measured by these items ( $P = .240$ ,

respectively,  $P = .439$ ). Less than half of the residents (44.8%) reported being competent when it came to advising patients specifically about the treatment of sexual dysfunction; again, there was no difference between male and female residents ( $P = .520$ ).

## Practice and Treatment for Sexual Dysfunction

To the question: “With which percentage of your prostate cancer patients did you discuss their sexual function in the past year?,” residents answered with an average of 56.8% patients ( $n = 85$ ; standard deviation 27.7; range 0%-100%). The average percentage of patients with whom sexual dysfunction was discussed did not differ between male and female residents (58% vs 55.8%,  $P = .713$ ). Table 3 presents the current practice regarding information provision and treatment of sexual dysfunction. Ninety percent of the residents ( $n = 78$ ) inquire about pre-existing ED before patients undergo prostate cancer treatment, with no difference in frequency of prescribing between male and female residents ( $P = .935$ ). Thirteen participants request that patients bring their partners for a consultation on sexual function (15.1%); 84.9% ( $n = 73$ ) does not.

**Table 3.** Answers to questions regarding practice patterns

	Often/ always	More than half of the cases	Half of the cases	Less than half of the cases	Never/ rarely
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Patients report sexual concerns by themselves	1 (1.1)	5 (5.7)	16 (18.4)	49 (56.3)	16 (18.4)
Informing patients about possible sexual side-effects	77 (88.5)	8 (9.2)	0 (0.0)	1 (1.1)	1 (1.1)
Asking about patients' sexual function during follow-up	29 (33.7)	26 (30.2)	12 (14.0)	15 (17.4)	4 (4.7)
Prescribing phosphodiesterase-5 inhibitors to patients with ED	22 (25.3)	23 (26.4)	27 (31.0)	13 (14.9)	2 (2.3)

ED, erectile dysfunction.

## Referral and Availability of Information Materials

Seventy-seven percent of the residents ( $n = 67$ ) were aware of where patients should be referred for counseling of complex sexual dysfunction. Most residents (54.0%) stated that they refer patients to a sexologist, 19.5% to a urologist–sexologist or andrologist, and 8.0% to an oncology nurse. Two residents reported referral to a pelvic floor therapist. Regarding responsibility within a department, 40.7% of the participants ( $n = 35$ ) reported that there are no agreements on who is responsible for discussing sexuality; 38.4% was unaware of such agreements ( $n = 33$ ). A minority of the residents were employed in a hospital where the task of addressing sexual concerns within the urology department was allocated ( $n = 18$ , 20.9%). According to 46% of the residents ( $n = 40$ ), information on treatment-related sexual dysfunction is available; 32.2% ( $n = 28$ ) was unaware of the presence of such documentation, and 21.8% ( $n = 19$ ) indicated that this material is not present in their hospital.

## Responsibility Among Treatment Team Members

Residents reported the urologist (n = 86, 98.9%), radiotherapist (n = 63, 72.4%), oncology nurse (n = 62, 71.3%), and the general practitioner (n = 35, 40.2%) as being most responsible in the area of diagnosis. During follow-up, the oncology nurse (n = 72, 82.8%), sexologist (n = 68, 78.2%), general practitioner (n = 59, 67.8%), psychologist (n = 47, 54%), and the pelvic floor physiotherapist (n = 38, 43.7%) were considered responsible for discussing sexuality with prostate cancer patients.

## Obstacles Preventing Sexual Communication

The reasons for residents not discussing sexual concerns with their prostate cancer patients were: “lack of time during a consultation” (67.1%), “lack of training” (35.3%), “language or ethnicity barrier” (34.1%), “the patient is too ill” (31.8%), “presence of a third party” (24.7%), “advanced age of the patient” (24.7%), and “surviving is more important” (20%).

## Implementing Sexual Health Care

The residents were asked to indicate which factors would be helpful in implementing sexual health care for men with prostate cancer in their current practice. The most convenient solution would be the assistance of a nurse who routinely discusses sexual concerns with all prostate cancer patients (n = 65, 78.1%). A majority (n = 60, 72.4%) indicated that the availability of information material regarding treatment related to sexual dysfunction would be beneficial. More than half of the residents (n = 46, 54.8%) indicated that a practical training on how to discuss sexual problems would help them to initiate these discussions, as well as good referral options for patients with sexual concerns (n = 46, 54.8%).

# DISCUSSION

## Key Results

The purpose of this survey was to provide an insight into the current urology residency training and the confidence of residents in addressing and advising on sexual dysfunction. The most important results encompass an evident need for additional training on the counseling and treatment of sexual dysfunction in men facing prostate cancer. Regardless of the residency level, most trainees have never received sexual education, report a limited level of knowledge, and require a need for training. Residents do not regularly prescribe medication for erectile dysfunction and less than half of them feel competent to treat patients for sexual dysfunction. Almost every resident provides information regarding sexual dysfunction prior to treatment, yet addressing the subject during follow-up is not a matter of routine. Barriers to discussing sexual function were lack of time during a consultation, lack of training, language obstacles, and a severe degree of illness. Residents indicated that assistance of a nurse, extended availability of

information material, and additional practical training would assist them in routinely providing sexual health care.

## Comparison With Literature

Luján et al surveyed 140 urology residents from 19 European countries with regard to the management of premature ejaculation.<sup>15</sup> Supposing this is not a condition associated with prostate cancer treatment-related sexual dysfunction, it is a condition associated with the field of sexual issues. Likewise, the results of this survey showed that urology residents received insufficient education in sexual dysfunction. In 2012, a survey was carried out among Canadian urology chief residents regarding satisfaction with their surgical training.<sup>16</sup> It, however, also assessed level of training in andrology and sexual dysfunction. Of the graduated participants, 67.8% believed they received inadequate training in andrology and sexual dysfunction. Although the Canadian Urological Association might have different educational programs and training requirements compared to the European Board of Urology, the lack of training does not only seem to apply to the European situation. A survey among physician members of the American Urogynecologic Society<sup>17</sup> on addressing female sexual dysfunction showed that half of the respondents were not satisfied with their training in this subject and also that they did not consistently screen for female sexual dysfunction.<sup>17</sup> Participants in the current survey reported a lack of knowledge on prostate cancer-related sexual dysfunction regardless of residency year, an outcome that does not correspond to the expected learning curve during residency. As residents gain training and knowledge, they might also recognize gaps in their knowledge. The lack of training among residents conjointly indicates that education in sexual dysfunction is not adequately represented in undergraduate programs. Up-to-date research on the provision of sexual education within medical schools is, however, limited.<sup>18</sup> In 2008, for instance, a survey among 2261 students enrolled in MD degree granting in the United States and Canada was described.<sup>19</sup> More than half of the respondents (n = 1206) stated that they had not received sufficient training on how to address sexual concerns clinically, corresponding with our results. This finding indicates that training in sexual communication is already lacking among medical students, the phase before starting a residency. To prevent a knowledge gap between developments in sexual dysfunction treatments and clinical practical skills, education during an earlier phase could significantly enhance the feeling of competence in discussing sexual concerns among future physicians.

## Urology Residency

The specific skills covered during urology residency differ between individual training programs, as well as between countries and continents. In the Netherlands, urology training consists of 2 years' general surgery, followed by 4 years of urology training, covering benign and malignant diseases. During urology training, the residents regularly have independent patient consultations in both the outpatient and inpatient clinics. Current educational program provides a 1-day andrology training, where sexual dysfunction is a leading subject. Whether other training



on sexual dysfunction is attended, depends on the local training program. As reported by the Dutch learning objectives, a urologist should possess sufficient knowledge about male sexual dysfunction and should be able to diagnose adequately and treat the problem with medication or by surgery. Another important objective is that the urologist is able to adequately communicate about sexual dysfunction by taking a sexual history and explaining treatment possibilities. Minimum level of knowledge for European board-certified urologists is considered familiarity with all the European Association of Urology Guidelines. The European Association of Urology Guidelines on male sexual dysfunction pay significant attention to post-prostate cancer treatment ED.<sup>20</sup> All future urologists are supposed to receive adequate training on the subject to be able to advise and treat their patients. Although an evident lack of knowledge and wish for training among Dutch urology residents are presented here, it is not clear whether these results are applicable to other residency trainings or to what extent other training facilities address male sexual dysfunction.

### **Importance of Adequate Sexual Communication Skills**

Changes in sexual functioning as a result of prostate cancer treatment can severely affect the quality of life and influence the relationship with the partner.<sup>21, 22, 23, 24</sup> More than half of all men with prostate cancer reported being in great need of discussing sexuality issues with their healthcare professionals.<sup>25</sup> Furthermore, focus group research indicated that partners of men with prostate cancer had not sufficiently received emotional and psychological support.<sup>26</sup> Sexual function is as highly valued by patients as urinary control and more highly valued than other side effects and treatment characteristics.<sup>9</sup> Patients indicated that the provision of useful information and satisfactory interaction with their healthcare providers was a large part of their adaptation when it comes to changes in their sexuality.<sup>27</sup> The apparent need for information and psychosexual support reported by patients, and even more by their partners, endorses the fact that it is important that urologists are aware they should offer this crucial component of care.

### **Strengths and Limitations**

As all urology residents present at the national training course completed the questionnaire, a nonresponse bias was not induced. However, a social desirability bias could still be present, resulting in an under- or overestimation, as residents participated during a training day organized by the educational board. Furthermore, as the survey was conducted prior to a lecture on andrology, it is plausible that an increased focus on the subject of sexual dysfunction was introduced. A non-validated questionnaire has been used, as a validated instrument assessing the specific study aims is not available. Content or construct validity was not measured as the instrument was not developed for purposes other than this specific survey. This was a single-country survey, and so the results may not be representative of the European and worldwide situation. Still, the results demonstrate an evident problem which provides us with

future research topics regarding the current international educational program, both for urology residents as well as medical students opting for an MD degree.

## **Clinical Implications**

Considering that physicians from other medical specialties involved with prostate cancer patients (ie, radiation oncologists<sup>14</sup> and oncology nurses<sup>13</sup>) do not routinely advise men on treatment-related sexual dysfunction and generally refer to urologists and urology residents, urologists should feel competent to treat sexual dysfunction. Nevertheless, residents experience various barriers to communicating about this topic, mainly reporting a lack of time and practical training. The survey results implied that residents consider oncology nurses responsible and helpful in providing sexual health care for patients after prostate cancer treatment. Although the oncology nurse could play a significant role in signaling and discussing sexual issues, the etiology and medical treatment remain a physician's specialty and thus responsibility. Enhancement of the cooperation between trained nurses and urologists could save time and dramatically improve care. Regardless of a task allocation, the urologist is supposed to have sufficient knowledge of the underlying etiology and the treatment of sexual dysfunction. Education starts during medical school followed by urology residency. To reinforce residents' elemental knowledge and skills, institutions are urged to develop an intensified course and ensure that the subject is studied in depth during their training programs. It is recommended that all international residency trainings be checked for compliance with regard to the implementation of education on male sexual dysfunction.

## **CONCLUSION**

Urology residency trainings do not pay sufficient attention to sexual communication skills and the treatment of sexual dysfunction. The residents are in need of more knowledge and more practical training in sexual counseling. As adequate training is a requirement for managing sexual health problems, the education provided during urology residency should be enhanced for the benefit of prostate cancer patients and future urologists to improve confidence and competence in providing sexual health care. The development of a core curriculum for urology residencies, including full coverage of sexual communication skills, knowledge on the etiology of sexual dysfunction, and the treatment of sexual issues, should be a priority for program directors.

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# Chapter 7

*Discussing sexuality in the field of plastic and reconstructive surgery: a national survey of current practice in the Netherlands*

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## INTRODUCTION

Health care is increasingly being assessed by the outcomes as experienced by patients. In recent decades, an increasing number of patient-reported outcome (PRO) measures have been developed to measure experienced outcomes [1, 2]. The primary overall outcome of many measures is the quality of life as reported by the patient. Quality of life comprises a number of constructs of which psychosocial well-being and physical health are well-known concepts. Sexuality is an important constituent of quality of life, but is often overlooked by health care professionals [3].

Diseases, medical treatments, and body image disturbances are all known to possibly negatively affect sexuality. Breast cancer patients, for instance, frequently experience sexual problems as a result of impaired body image [4]. The impact of (surgical) treatments on experienced measures of sexuality (e.g., sexual (dys) function, sexual activity, and satisfaction with sexuality) is only recently being explored and has been largely under-addressed by physicians [3]. The field of plastic surgery is dedicated to reconstruction of bodily defects due to birth disorders, trauma, burns, and disease. Many plastic surgeons perform cosmetic surgical procedures as well, which are focused on enhancing a patient's appearance. Plastic and cosmetic surgery treatments typically have direct impact on esthetic appearance and may also affect sensation. Outcomes of plastic surgical treatments can be strongly associated with psychosocial factors including one's body image [5]. Therefore, many plastic or cosmetic surgical treatments can also impact sexual function, which has been objectified for gynecomastia correction or cleft lip-palate surgery for example [6, 7]. In addition, it has been shown that the outcomes of breast reconstruction, which is the most frequently performed reconstructive procedure in Western society, are strongly related to measures of sexuality [4, 8].

Traditionally, (plastic) surgeons are primarily trained in the technical aspects of their profession. They are educated to deal with the physical problems, whether functional or cosmetic and their consequences for daily functioning. Addressing problems at another functional level, such as sexual function, requires additional knowledge, but also additional time. From former studies, we do know that addressing the topic is difficult for the patient as well as the physician due to several barriers including insecurity because of lack of knowledge [3, 9]. Presently, it is not known to what extent plastic surgeons address or discuss issues concerning sexuality with their patients. Here, we aim to identify the current plastic surgery practice in the Netherlands. In addition, we assess if there is a need for improvement from the plastic surgeon's point of view.

## METHODS

### Study design

In November 2016, a national survey was conducted in which all plastic surgeons and plastic surgery residents practicing in the Netherlands ( $n=385$ ) were approached via post mail to



participate. The surveys were accompanied by an information letter and a post-paid return envelope. Addresses were obtained via the Dutch Society of Plastic Surgery (NVPC), which gave permission to send a one-off mailing only. Therefore, no reminders were sent. Data were collected and processed anonymously. Data collection was closed after 3 months.

## Development of the survey

The authors developed the survey in line with a previously developed instrument of similar kind [10]. The survey comprised 34 items, which focused on the background and experience of the plastic surgeon, as well as their practice related to discussing sexual functioning with their patients, their preferences with regard to sexuality training, and their interest in other sexuality support. The final survey included the following sections:

1. A demographic sheet assessing professional background (including interest areas within plastic surgery, clinical setting), years of experience in plastic surgical practice, gender, and age.
2. Several questions were asked about the frequency respondents discussed the subject of sexuality with their patients (at preoperative informed consent and postoperative follow-up consultations; 5-point Likert scale ranging from “never” to “always” and in percentages) and ways of discussing the subject (e.g., roles of team members).
3. A section on opinions about the importance of the topic of sexuality in their work (4-point Likert scales ranging from “not important” to “very important”), the responsibilities of the plastic surgeon, on past and ideal clinical training, and on (practical) barriers towards discussing the topic (“what is preventing you to talk about sexuality with your patients?”: e.g., patient age/ethnicity, duration of the consultation, insecurity or shame of the surgeon; disagree/neutral/agree answering options).

The present instrument was modified after a survey assessing similar subjects in another field of medicine [10]. A first version of the current measure, based on this scientifically valid tool described earlier, was tested in a pilot study in which five plastic surgeons provided feedback on the clarity and content of the questions. Based on their remarks, minor adjustments were made to the survey, resulting in the final instrument.

## Statistical analysis

Data analysis was performed using SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp. Descriptive statistics were used to describe the outcomes. Equality of proportions between types of surgeons was tested with Pearson’s chi-square test or Mantel Haenszel test for trend, if groups were ordinal. Two-sided  $p$  values  $< 0.05$  were considered statistically significant. In the questionnaire, surgeons could fill in more than one subspecialty. Per individual subspecialty calculations were made. Therefore, total sums of some analyses can add up to more than the total amount of participants.

## Ethical approval

As this study did not involve patients nor interventions and participation to this study was voluntarily, formal ethical approval was not required in the Netherlands.

## RESULTS

### Participants

From a total of 385 members of the Dutch Society of Plastic Surgery, 106 plastic surgeons and residents returned a completed survey (27.5%). Two responding plastic surgeons stated they did not complete the survey because they considered the subject not applicable to their practice. The median age of the participants was 44 (range 29–66) years and 71.1% of the participants were male. The majority reported at least 5 years of experience in plastic surgery (91.5%); 14 respondents were residents in training (13.2%). Areas of interest and clinical settings are displayed in Table 1.

### Discussing sexuality with patients

Most respondents (78.3%) reported they rarely or never discussed subjects regarding sexuality (Table 2). Both during preoperative informed consent consults as well as during clinical follow-up visits after surgery, sexual function was rarely or never being discussed (79.3%, 80.5%). When looking per subspecialty, plastic surgeons specializing in genital or gender surgery stated that they discussed sexuality with almost all patients. In all other subspecialties, this was the case in 5% or less of the patients (Table 3). When focusing on breast surgery specifically, cosmetic surgeons stated they rarely or never discussed sexuality with patients opting for breast reduction (55.2%) or breast augmentation (69.0%) respectively. In addition, 70.4% of surgeons rarely or never discussed the topic with patients who require breast reconstruction (Table 4). Yet, 61% of all responding participants mentioned that sexuality should be discussed at least once with patients undergoing breast surgery. More than half of the respondents (55.7%) stated that it is (very) important to inform patients about sexual complaints relating to surgical interventions. Twenty-six of the respondents mentioned they had referred at least one patient to a specialized sexuality care professional. When asked “what is preventing you to talk about sexuality with your patients?”, reasons that were confirmed most often were that there was no reason to discuss sexuality (47.6%), that they received insufficient training (40.3%), and that they experienced a lack of knowledge (40.3%) (Fig. 1). When being asked what could help the respondents to address sexual problems, “reading material for patients” was most frequently selected (Fig. 2). Among the respondents that did discuss sexual function, insecurity due to a changed self-image or appearance was the most frequently discussed topic ( $n = 41$ , 66.1%).

**Table 1.** Demographic characteristics (n=106), n (%)

Age (range), median in years	44 (29-66)
Gender	
Male	76 (71.1)
Female	30 (28.3)
Experience (including residency)	
0-5 years	9 (9.5)
6-10 years	30 (28.3)
>10 years	67 (63.2)
Function	
Plastic surgeon	92 (86.8)
Resident plastic surgery	14 (13.2)
Clinical setting	
University hospital	30 (28.3)
Top clinical teaching hospital	5 (4.7)
District general hospital	33 (31.1)
Private clinic	26 (24.5)
Categorical cancer hospital	1 (0.9)
Areas of interest*	
Breast reconstructive surgery (oncology)	77 (72.6)
Hand and wrist surgery	64 (60.4)
Cosmetic surgery	54 (50.9)
Head and neck reconstructive surgery	24 (22.6)
Genital surgery	19 (17.9)
Paediatric surgery	14 (13.2)
Burn reconstructive surgery	8 (7.5)
Gender surgery	5 (4.7)
Post bariatric surgery	2 (1.9)
Perianal reconstruction	1 (0.9)

\* Multiple answers possible

**Table 2.** Discussing sexuality with patients

	n*	(Almost) never	In less than 50%	In more than 50%	(Almost) always
How often do you discuss the patients' sexual health?	106	78.3%	18.9%	0.9%	1.9%
Do you inform patients about consequences of surgery for sexual function during the informed consent procedure?	105	79.0%	16.2%	1.0%	3.8%
How often do you address sexual health during follow-up visits?	61	80.5%	12.2%	4.8%	2.4%
	n*	Not important	Somewhat important	Important	Very important
How important is it to inform patients about possible sexual complaints?	104	1.0%	43.3%	41.3%	14.4%

\*Number of responders for this specific question

**Table 3.** In the past year, with which percentage of your patients did you discuss topics related to sexuality (per subspecialty)?

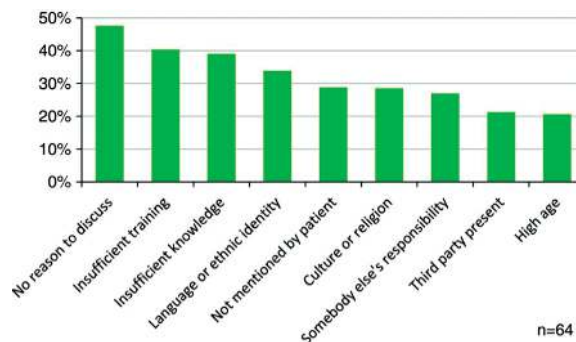
Specialty	n*	Percentage Median (IQR)
Breast reconstruction	71	5 (15)
Head and neck	20	0 (0)
Gender	5	95 (25)
Genital	9	100 (0)
Hand and wrist	49	0 (0)
Burns	6	0 (6)
Cosmetic	47	5 (15)

\*Number of plastic surgeons who treat patients within this subspecialty

**Table 4.** Discussing sexuality with breast surgery patients

How often do you inform women about (the consequences on) sexuality when they undergo					
	n*	Never	Rarely	Regularly	Often
- Breast Reconstruction?	44	22.7%	47.7%	18.2%	11.4%
- Breast Reduction?	29	41.4%	13.8%	27.6%	17.2%
- Breast Augmentation?	29	34.5%	34.5%	17.2%	13.8%

\*Only plastic surgeons working in the relevant subspecialty were included



**Fig 1.** What prevents you from discussing sexuality with patients?

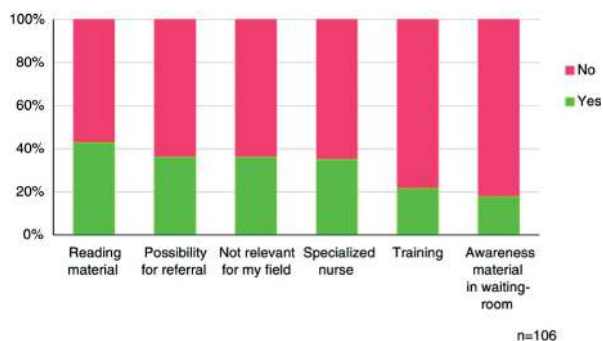


Fig 2. This could help me to discuss sexuality with patients

## Responsibility, knowledge, and training

Almost half of the respondents (49.1%) thought that plastic surgeons do have a responsibility to discuss sexuality-related issues with their patients. Although not applicable to all patient groups, oncological nurses and the oncological surgeon were also thought to have a responsibility to discuss the topic with the patient (Fig. 3). Only 6.1% of plastic surgeons stated that they had sufficient knowledge on sexual (dys)functions, while 86.2% stated that they had only little or no knowledge at all on the subject (Table 5). The majority of the respondents (64.7%) believed that sexuality was not adequately addressed during plastic surgery residency, yet only 6.1% underwent additional training. A minority of all participants (21.4%) was interested to learn more about the subject. This interest was significantly more expressed by participants who were still resident, when compared to plastic surgeons (50% vs. 16.9%,  $p = 0.01$ , Fisher's exact test).

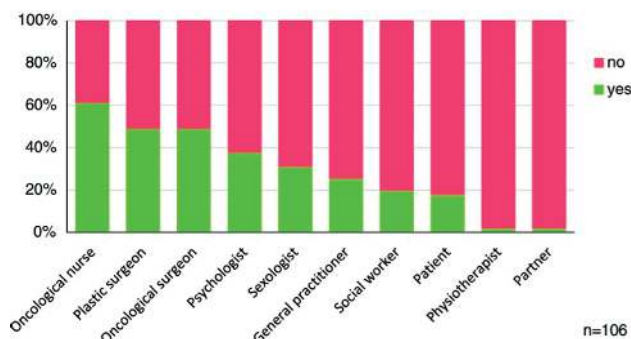


Fig 3. Who is responsible for raising sexuality as a discussion topic in the plastic reconstructive surgery practice?

**Table 5.** Knowledge and training

	<b>n</b>	<b>None (%)</b>	<b>A little (%)</b>	<b>Some (%)</b>	<b>Sufficient (%)</b>
Do you have knowledge on sexual dysfunctions and treatments?	66	15.2	53.0	25.8	6.1
	<b>n</b>	<b>Yes (%)</b>	<b>No (%)</b>		
Do you think that sexology is adequately addressed during plastic surgery residency?	102	35.3	64.7		
Did you have additional training on how to address sexual problems of patients?	66	6.1	93.9		
Would you like to improve your skills with regard to addressing sexual health problems?	103	21.4	78.6		

## DISCUSSION

The present study is the first to report on what role sexuality plays in the plastic surgeon's consultation room. The data show that plastic surgeons infrequently discuss sexual functioning with their patients, with genital and gender subspecialists as the exception. Breast surgeons and cosmetic surgeons, two significant subspecialties within plastic surgery, generally agreed that sexuality is important for their surgery/population and that they carry a responsibility to discuss the topic. Still, many rarely discussed the subject with patients. Plastic surgeons experienced uncertainty on conversation starters, insufficient training, and limited knowledge as important barriers towards discussing the subject, and viewed the oncological nurse and psychologist as more appropriate team members to raise this topic. Hereafter, these findings will be discussed in the light of (1) the role of sexuality in plastic surgery practice, (2) how current practice on this topic relates to other specialties, (3) what structural barriers towards discussing sexuality in medical practice are currently known, and (4) how clinical services in plastic surgery may be improved regarding our present findings.

It is known that within the plastic reconstructive surgery population, sexuality can play an important role. Sexuality issues in general can derive from impaired body image, loss of sensation or (sexual) function of body parts, or partnership issues [5]. In breast cancer patients, for example, sexuality was found to be significantly impaired [4, 8]. This relationship between symptoms or consequences of surgery and sexuality also applies to other types of plastic surgery patient groups such as the people undergoing genital reconstructive surgery (incl. transgender individuals), cosmetic, burn, and even hand surgery populations [11–17]. Restoring an impaired (genital) body image can be a primary motivation for patients to opt for plastic reconstructive surgery [18–20]. In contrast to what patients may experience, many surgeons (possibly including many non-responders of this study) assume that sexuality is not an issue within their patient population.

Our data confirm that in current plastic reconstructive surgery practice in the Netherlands, sexuality is only rarely discussed. An explanation for this could be the existence of experienced boundaries to start the discussion, from both the patient's and a surgeon's point of view. Genital and gender surgeons indicated they integrate the topic more frequently than their colleagues from other relevant subspecialties such as breast surgeons. Possibly, this percentage was higher because of the surgeon's assumption that sexuality is only relevant for surgeries in genital regions. However, the impact of other sexuality-related body parts should not be underestimated. Although sexuality applies to breast surgery very much [21], other medical specialties have also recognized the importance for sexuality in their practice, for example in urology, gynecology, but also in cardiology [10, 22–27]. Comparable studies to the present study in other fields of medicine show an equal lack of discussing sexology as well as the associated boundaries [10, 22–27]. It is positive that contemporary literature does emphasize these issues and attempts to invoke a responsibility among providers who treat patients with pathology in relevant areas. The discrepancy between patient experiences and physician assumptions underlines the importance of good basic knowledge in signaling of and counseling on sexuality issues within the plastic reconstructive surgery practice. It is important that surgeons are aware that sexuality can play a role within unexpected patient populations as well.

Findings in our study suggest that there exist structural barriers towards starting the conversation on sexuality within plastic surgery practice. These barriers may exist for both the patients and the health care providers. Earlier studies have found that the biggest barriers on this subject are formed by inadequate training, lack of knowledge, insecurity, and disbelief in treatment options [28–30]. In other studies, it was shown that years of clinical experience, provider age, a history of training regarding sexual dysfunction, and an international setting of practice positively impact providers' opinions and practices towards sexual issues of patients [23, 24, 27]. Also, fear of causing distress was found to be associated [25]. In our study, we confirmed many of the aforementioned factors for the Dutch plastic surgery practice. In addition, we also observed the existence of (false) assumptions regarding sexuality (e.g., “sex is not related to the condition that I treat,” “sexuality does not apply to certain age groups,” and “if the patients do not mention the topic, there is no issue”). In addition, the complexity of sexual function may not be sufficiently captured in the short time physicians have for their consultation [31].

Based on our findings, we can propose several suggestions to improve clinical services for future patients in plastic surgery with (possible) sexuality issues. We found that plastic surgeons and residents felt insufficiently trained on this topic and had little time to address the topic of sexuality with their patients. Also, respondents expressed a wish for written patient information material on this subject. In order to facilitate plastic surgeons in their discussion of this topic, it is essential to provide them with good patient information material that addresses the topic, lowers the threshold to discuss the topic, and provides all parties with good referral options [3]. In addition, we found that plastic surgeons feel that they carry a responsibility

to signal and address sexuality. Subsequently, specialized psychologists or nurses best perform the treatment of existing sexuality issues. Oncology nurses for example have shown to play an important role in repeatedly question patients on this topic [9, 10]. Though, it is important to stress that this profession is not involved in the treatment of the non-oncological plastic surgery population. In these non-oncological patient groups, plastic surgeons do carry the responsibility to signal sexology issues. It is therefore helpful to collaborate interdisciplinary and provide a solid referral routing network. Plastic and reconstructive surgery is a multidisciplinary specialty and facilities already exist for non-sexuality domains. Judging from our results, we can expect more affinity with the topic from the younger generation of plastic reconstructive surgeons. Investing in (continued) training on sexuality and in the residency program can contribute as well. By initiating the discussion, clinicians have the potential to detect sexual dysfunction and to refer adequately when necessary, thereby improving overall quality of life of their patients [3, 26, 32]. Ideally, standardized outcome measures such as the BREAST-Q will further objectify this improved (sexual) quality of life [2].

The strength of this study includes the fact that it is the first nationwide survey on this subject and that we have reached a significant number of plastic surgeons from different fields. Limitations include the moderate response rate and number of missing data. The national plastic surgeons society permitted us to send only a single mail, which may partly explain the moderate response rate. Still, the response rate is comparable to other survey studies [10]. The included study population was relatively heterogeneous as no selection was performed based on subspecialty and/or years of experience (due to the study aim of generating an overview of the plastic surgical field as a whole). Therefore, plastic surgeons without interest in sexuality may not have responded, possibly making our findings less generalizable. In-depth interviews could help gaining a better understanding of the difficulties plastic surgeons encounter when they start talking about sexuality. For future studies, a larger number of participants could enable a more detailed analysis per subspecialty and/or other confounders such as years of experience, clinical training, and socio-cultural background. An example of such a study could be a pan-European study. At the end of the present survey, the proportion of missing data increased, most likely caused by the length of the survey and the detailed questions. Surgeons who do not integrate sexuality in their professional practice may have been less likely to complete the survey. Based on the present findings, a future survey should be shorter and cover the main topics only.

## CONCLUSIONS

In plastic surgery practice, sexuality appears to be a rarely discussed subject (with gender and genital surgery subspecialties as the exception). Although scholars and patients emphasize the importance of sexuality in postoperative quality of life, plastic surgeons express limited urge to



be trained in this subject and prefer patient information and referrals. To improve early detection of sexual issues and create a safe space for patients to discuss the topic with their surgeons, the authors stimulate more education on sexuality during plastic surgery training.

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# Chapter 8

*Written information material and availability of sexual health care for men experiencing sexual dysfunction after prostate cancer treatment: An evaluation of Dutch urology and radiotherapy departments*

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## INTRODUCTION

Prostate cancer is one of the most common malignancies among men. Approximately 11,000 new cases are diagnosed in the Netherlands each year (Netherlands Comprehensive Cancer Organisation (IKNL), 2016). Due to early screening for prostate-specific antigen (PSA) and improved treatment results, the 5-year survival rate extends up to 88% (Netherlands Comprehensive Cancer Organisation (IKNL), 2014). Treatment options differ according to disease stage and patient's preference. Depending on Gleason score, tumour volume and PSA level, patients with localised disease (stage T1c–T2c, N0, M0) are eligible for active surveillance, radical prostatectomy (RP), external beam radiotherapy (EBRT) or brachytherapy (BT) (Heidenreich et al., 2014). In case of extensive disease, eligible treatment consists of androgen deprivation therapy (ADT), implicating bilateral orchiectomy, luteinising hormone-releasing hormone agonists, antagonists or anti-androgens (Heidenreich et al., 2014; White et al., 2015).

Sexual dysfunction (SD), in particular erectile dysfunction (ED), is in addition to incontinence one of the most common side effects of prostate cancer treatment (Potosky et al., 2004). Additional sexual side effects include decreased libido, orgasm impairment and diminished ejaculation or anejaculation (Chung & Brock, 2013). After RP (laparoscopic, open procedure or robot-assisted) rate of ED varies between 25% and 90%, up to 64% after EBRT and 50% after BT depending on, for example, erectile function prior to treatment (Chung & Brock, 2013; Merrick et al., 2005; Tutolo et al., 2012). Erectile function is affected in up to 85% of patients receiving ADT (White et al., 2015).

Disease recurrence has the primary focus during follow-up consultations rather than the impact of treatment-related side effects, such as SD. Evidence has shown that SD fundamentally affects the quality of life and romantic relationship between patient and partner. The disease itself and coping with its consequences is considered as a “relationship disease,” as partners may experience psychosocial issues as well, resulting in decrease in quality of life (Garos, Kluck, & Aronoff, 2007; Meyer, Gillatt, Lockyer, & Macdonagh, 2003). In a cohort of 165 partners of men with prostate cancer, significant more distress was reported by partners, implicating the necessity to discuss an altered sexual function after prostate cancer treatment and importance of extensive and comprehensive information material for both patients and partners (Eton, Lepore, & Helgeson, 2005; Knight & Latini, 2009). Nevertheless, the content of written information material regarding sexuality throughout prostate cancer treatment has not been investigated previously.

Besides adequate information material, sexual health care becomes utterly relevant when it comes to guidance in altered sexuality after treatment. Several ED treatment options are available, such as PDE5 inhibitors, intraurethral prostaglandins, penile injection therapy or vacuum devices (Megaw et al., 2013). Despite this availability, treatment should also focus on the psychological aspect of altered intimacy between patient and partner. Thereupon, psychosexual support can be implemented when changes in the relationship are experienced



by men with prostate cancer and their partners, meaning both aspects of SD treatment are essential and should be available at departments within corresponding hospital or clinic. As such, knowledge about reference possibilities for corresponding departments would be convenient in case specialised sexual health care is needed.

The aim was to evaluate the content of written information material concerning sexual side effects provided to men with prostate cancer throughout treatment by Dutch urology and radiotherapy departments. In addition, the availability of sexual health care for patients experiencing treatment-related SD was investigated.

## METHODS

### Study design

A cross-sectional survey was conducted among Dutch urology and radiotherapy departments to evaluate the content of written information material for men with prostate cancer provided throughout RP, BT, EBRT or hormone therapy treatment. Also, the availability of sexual health care was evaluated for men experiencing SD after treatment. Data were collected by administering short interviews by phone or email along with collecting and scoring of written information material on content regarding sexual health after prostate cancer treatment provided by Dutch urology and radiotherapy departments.

### Data collection

All Dutch urological outpatient clinics ( $n = 88$ ), radiotherapy departments ( $n = 14$ ) and independent radiotherapy clinics ( $n = 6$ ) were primarily contacted by phone. Hospitals or clinics were excluded in case of unavailability of RP, BT or EBRT treatment ( $n = 37$ ). From May 2015 until July 2015 all eligible hospitals and/or clinics ( $n = 71$ ) were approached telephonically to participate in our survey, in which anonymity was ensured. A questionnaire developed by the authors was administered by phone or sent by email after telephonic inquiry (Appendix A). Main topics included type and timing of information material provision, available ED treatment options and knowledge concerning referral possibilities. Furthermore, participating departments were asked to send all available brochures regarding prostate cancer treatment by mail. After two weeks, non-responders were contacted by phone or a reminder was sent by email, depending on the initial approach. A second reminder by phone or email was performed after four weeks. Received written information material was collected as well as brochures presented on their websites, prior to permission of the concerning department to download and print their information material. If permission was not received, brochures of unwilling departments were not collected despite the availability of information material online. Appendix A. Questionnaire administered among urology and radiotherapy departments.

1. Do you provide information material regarding treatment and its side effects to men who will undergo prostate cancer treatment?
2. What type of information material does it concern?
3. Do patients receive information material routinely or is it provided upon request?
4. Who is responsible for the provision of information material to patients?
5. Which treatment options are available at your hospital or clinic?
6. Does the department provide pre-treatment nurse consultations where sexual health is discussed in context of informed consent?
7. Does the department provide sexual health care for patients experiencing altered sexuality after prostate cancer treatment?
8. Do you know where patients are referred to when altered sexuality is experienced after prostate cancer treatment?
9. Is your department able to send us available written information material regarding prostate cancer treatment?

## Categorisation and scoring

Collected written information material was reviewed and scored for content by two independent researchers according to in advance determined categories, mainly concerning in to what extent SD after prostate cancer treatment and ED treatment options are discussed (all categories are displayed in detail in Table 1). A third independent researcher checked the agreeability of the first scoring researchers. If agreement was not obtained on independent items, deliberation took place until agreement was achieved. Each category was scored on a scale from 1 to 3 regarding quantity of information on sexuality: (1) extensive amount of information, (2) moderate amount of information and (3) little or no information. Accordingly, points credited to each category were summed leading to a total score per brochure. Written information material containing information about different types of treatments was grouped in category “general information material”. In case participating departments had sent multiple brochures, written information material was categorised regarding type of treatment. If various departments provided identical information material, brochures were analysed separately.

## Statistic methods

Data analysis was performed using spss Statistics Version 23 (SPSS Inc., Chicago, IL, USA). Descriptive statistics and frequency analyses were used to calculate the results of administered interviews and the scored content of received written information material. Differences between specific answers and scoring results of information material categorisation were identified using Pearson’s Chi-Square test, Fisher’s Exact test and Cochran-Armitage Trend test. Statistical significance was defined as  $p < .05$ .

**Table 1.** Categories and corresponding score of written information material content

	Score
<b>Sexual side effects resulting from treatment are discussed</b>	
Yes, discussed in separate chapter	1
Yes, discussed in side effects section	2
Not discussed	3
<b>Influence of treatment on erectile function is described</b>	
Yes, described and statistics are presented	1
Yes, described although statistics are not presented	2
Not described	3
<b>Influence of treatment on ejaculation is described</b>	
Yes, described and aetiology is discussed	1
Yes, described although aetiology is not discussed	2
Not described	3
<b>Aetiology of SD subsequent to treatment is discussed</b>	
Yes, both mental and physical causes are discussed	1
Yes, although only physical causes are discussed	2
No description	3
<b>Information concerning several types of ED treatment options</b>	
Yes, information is given and examples are listed	1
Yes, information is given although advice is not presented	2
No information is given	3
<b>Information concerning SD and its possible effect on relationship</b>	
Yes, information is given and advice is presented	1
Yes, information is given although advice is not presented	2
No information	3
<b>Partner is mentioned in context of intimacy and sexuality</b>	
Yes, partner is mentioned and specific information is given	1
Yes, partner is mentioned although specific information is not given	2
Not mentioned	3
<b>Mention of sexual counselling and provision of contact details</b>	
Yes, mentioned and contact details are given	1
Yes, mentioned although contact details are not given	2
Not mentioned	3

## Ethical considerations

Official approval was received by local Research Ethics Committee of the Department of Urology of Leiden University Medical Center. Participation was voluntary and results were analysed anonymously.

## RESULTS

### Participating clinics

Out of 71 eligible departments, a total of 49 departments consisting of 34 urology departments and 15 radiotherapy departments agreed to participate, resulting in a response rate of 69.0%. Thirty-two departments completed the questionnaire by phone and 17 by email. Thirty-two urology departments and 14 radiotherapy departments conceded to send their written information material. However, a small part of written information material never arrived despite sending was confirmed by concerning departments ( $n = 4$ ). A total of 59 written items were received corresponding to 42 participating departments.

### Questionnaires

To the question whether written information material was provided to patients throughout prostate cancer treatment, all participating departments ( $n = 49$ ) answered positively. Brochures as information material were provided most frequently (Table 2). Although not significant, urology departments (39.1%) had, in comparison to radiotherapy departments (8.7%), more brochures available regarding sexuality throughout prostate cancer treatment ( $p = .197$ , Fisher's Exact test). Pre-treatment nurse consultation, where sexuality is specifically discussed as a part of informed consent, was found to be more available at urology than radiotherapy departments ( $p < .01$ , Pearson's Chi-Square test).

Urology departments had more sexual counselling possibilities for patients experiencing SD after treatment in comparison to radiotherapy departments ( $p < .05$ , Fisher's Exact test). In case of absence of sexual health care within the corresponding department, all participating urology departments were aware of external referral possibilities (both within hospital or clinic and external location) for patients experiencing SD. Of all participating radiotherapy departments, 66.7% were aware of referral possibilities. Urology departments referred patients more frequently to a medical sexologist as to radiotherapy departments ( $p < .001$ , Fisher's Exact test), whereas radiotherapy departments referred patients more often to a urologist than urology departments ( $p < .01$ , Fisher's Exact test). A significant majority of all participating departments had referral possibilities for patients within their own hospital or clinic ( $p < .02$ , Likelihood Ratio), particularly departments of academic and top clinical hospitals ( $p < .001$ , Linear-by-linear Association). Three urology departments had both sexual counselling within the corresponding department as well as possibilities to refer patients to an external location.

**Table 2.** Results of administered questionnaires concerning sexual health care provision

Characteristics	Urology	Radiotherapy	<i>p-value</i>
	(n = 34) <i>n</i> (%)	(n = 15) <i>n</i> (%)	
Availability of treatment-specific information material <sup>a</sup>	73 (76.0)	23 (24.0)	
Brochures	32 (43.8)	14 (60.9)	<i>NS</i> <sup>b</sup>
Prostate cancer guidebook	4 (24.7)	3 (13.0)	<i>NS</i> <sup>b</sup>
Website information material	9 (12.3)	6 (26.1)	<i>NS</i> <sup>c</sup>
Personal patient information file	9 (12.3)	-	<.05 <sup>b</sup>
Other	5 (6.8)	-	<i>NS</i> <sup>b</sup>
Availability of general information material	18 (52.9)	4 (26.7)	<i>NS</i> <sup>b</sup>
Brochures created by corresponding hospital or clinic	5 (27.8)	-	<i>NS</i> <sup>b</sup>
Dutch Cancer Society (KWF)	9 (50.0)	2 (50.0)	<i>NS</i> <sup>b</sup>
‘Cancer and sexuality’	4 (22.2)	2 (50.0)	<i>NS</i> <sup>b</sup>
Pre-treatment nurse consultation <sup>d</sup>	31 (91.2)	8 (53.3)	<0.01 <sup>c</sup>
Availability of sexual counselling within department	14 (41.2)	1 (6.7)	<.05 <sup>b</sup>
Physician	8 (57.1)	1 (100.0)	<i>NS</i> <sup>b</sup>
Nurse/nurse practitioner	6 (17.6)	-	<i>NS</i> <sup>b</sup>
Referral possibility known	34 (100.0)	10 (66.7)	<.001 <sup>c</sup>
Within hospital/clinic	23 (67.6)	9 (90.0)	<i>NS</i> <sup>c</sup>
Sexologist	17 (73.9)	2 (22.2)	<.05 <sup>b</sup>
Urologist	3 (13.0)	6 (66.7)	<.01 <sup>b</sup>
Psychologist	4 (17.4)	-	<i>NS</i> <sup>d</sup>
Other	3 (13.0) <sup>e</sup>	2 (22.2) <sup>e</sup>	<i>NS</i> <sup>b</sup>
External location	14 (41.2)	1 (90.0)	<i>NS</i> <sup>b</sup>
Sexologist	12 (85.7)	-	<i>NS</i> <sup>b</sup>
Psychologist	1 (7.1)	-	<i>NS</i> <sup>b</sup>
Other	2 (14.3) <sup>e</sup>	1 (100.0) <sup>e</sup>	<i>NS</i> <sup>b</sup>

NS: Not significant

a) Some departments provided multiple brochures

b) Fisher's exact test

c) Pearson's chi square test

d) Consultation in which sexuality is specifically addressed as a part of informed consent

e) Including (one) urologist-sexologist

## Comparison of written information material among departments

A significant difference was found between urology and radiotherapy departments regarding the content of written information material when it comes to treatment-related SD. Urology departments provided more extensive information material in comparison to radiotherapy departments ( $p < .05$ , Cochrane-Armitage Trend test). Further categories of received information material are displayed in Table 3. Moreover, significant more extensive information was found in brochures concerning sexual side effects throughout RP than brochures concerning sexual side effects around BT and EBRT ( $p < .05$ , Cochrane-Armitage Trend test).

**Table 3.** Categories of content regarding received written information material

Information material	Urology (n = 38) n (%)	Radiotherapy (n = 21) n (%)	p-value
Discussing sexuality	37 (97.4)	15 (71.4)	<.01 <sup>a</sup>
Separate chapter	23 (62.2)	9 (60.0)	
Appointed among side effects	14 (37.8)	6 (40.0)	
Discussing impact of treatment on erectile function	36 (94.7)	11 (52.4)	<.001 <sup>a</sup>
Percentages named	13 (36.1)	4 (36.4)	
No percentages named	23 (63.9)	7 (63.6)	
Discussing impact of treatment on ejaculation	28 (73.7)	6 (28.6)	<.001 <sup>a</sup>
Cause named	15 (53.6)	2 (33.3)	
No cause named	13 (46.4)	4 (66.7)	
Discussing aetiology of SD	28 (73.7)	7 (33.3)	<.01 <sup>a</sup>
Physical and mental causes	11 (39.3)	5 (71.4)	
Physical causes only	17 (60.7)	2 (28.6)	
Discussing treatment options for erectile dysfunction (ED)	20 (52.6)	2 (9.5)	<.01 <sup>b</sup>
Examples named	12 (60.0)	1 (50.0)	
No examples named	8 (40.0)	1 (50.0)	
Discussing impact of SD on relationship	8 (21.1)	2 (9.5)	NS <sup>c</sup>
Named options for help	6 (75.0)	2 (100.0)	
Named no options for help	2 (25.0)	-	
Partner mentioned in the context of intimacy and sexuality	10 (26.3)	5 (23.8)	NS <sup>c</sup>
Specific partner information	-	-	
Partner mentioned only	10 (100.0)	5 (100.0)	
In case of questions about sexuality	18 (47.4)	8 (38.1)	NS <sup>c</sup>
Contact person with details named	1 (5.6)	1 (12.5)	
Contact person named without details	17 (94.4)	7 (87.5)	
Amount of information			
Extensive (10 – 14 points)	10 (26.3)	2 (9.5)	<.05 <sup>c</sup>
Moderate (15 – 20 points)	21 (55.3)	9 (42.9)	
Little or no (21 – 25 points)	7 (18.4)	10 (47.6)	

NS: Not significant

a) Pearson's Chi-square test

b) Fisher's exact test

c) Cochran-Armitage trend test

With regard to the influence of SD to the romantic relationship and intimacy between patient and partner, 21.1% of urology departments and less than 10.0% of radiotherapy departments discussed this subject in written information material. Around one-fourth of urology and radiotherapy departments (respectively 26.3% and 23.8%) mentioned partners of men with

prostate cancer. However, none of them provided specific information for partners regarding the impact of SD on the romantic relationship and intimacy.

## DISCUSSION

### Key results

This study shows that treatment-related SD is discussed into highly varying degrees in written information material coming from Dutch urology and radiotherapy departments. Furthermore, it shows that sexual health care is currently not available in every hospital or clinic where prostate cancer is treated.

Although all participating departments provide written information material, it appears that sexuality is discussed more frequently and more extensively in written information material coming from urology departments in comparison to radiotherapy departments. Thereby, all brochures contain more extensive information concerning altered sexuality after RP compared with altered sexuality after BT and/or EBRT. Although ED rate is higher after RP in comparison to after BT and/or EBRT, the possibility of SD as a result of radiation therapy is still highly present. Availability of ED treatment options is mentioned in only half of written information material, whereas in even fewer brochures examples of ED treatment options are specified. Partners of men with prostate cancer are not extensively mentioned in written information material, although impact of SD on the romantic relationship between patient and partner is well known (Letts, Tamlyn, & Byers, 2010).

The availability of sexual health care varies among Dutch urology and radiotherapy departments. Moreover, referral systems of various hospitals are not organised in a similar way when it comes to men experiencing treatment-related SD. Urology departments dispose of more sexual counselling in order to treat ED than radiotherapy departments. If sexual counselling is not available in their own hospital or clinic, all urology departments know where to refer patients in comparison to only half of all radiotherapy departments. Likewise, urology departments provide pre-nurse consultation where sexuality and treatment-related SD is discussed more often than radiotherapy departments.

### Comparison with literature

This study is the first to investigate the content of written information material concerning intimacy and sexuality provided to men undergoing prostate cancer treatment. However, a few studies investigated the general content of written information material regarding prostate cancer treatment. Rees, Ford, and Sheard (2003) reported poor quality of written information material in general. Unfortunately, the content concerning sexuality in particular, was not mentioned in this study. Walling, Maliski, Bogorad, and Litwin (2004) described insufficient and inaccurate written information material concerning treatment management and disease-

related symptoms. Seventy-nine per cent of brochures regarding RP were reported to mention impotence. Nevertheless, only 18% of all brochures provided specific information concerning this topic. Weintraub, Maliski, Fink, Choe, and Litwin (2004) evaluated written information material through the Suitability Assessment of Materials (SAM) rating scale. SAM is an instrument to measure suitability in terms of content, literacy demand, graphics and layout (Doak, Doak, & Root, 1996). Written information material investigated in this study scored poorly on content and self-efficacy and did not include sexuality as a specific topic.

Krouwel et al. (2015) investigated the role of radiation oncologists concerning the discussion of sexual function after (pelvic) radiation. Out of 119 participating radiation oncologists, 29.2% reported the referring physician as responsible for informing patients regarding possible treatment-related sexual side effects. Additionally, 13.8% of radiotherapists stated treatment-related SD should be discussed and treated by concerning general practitioner. Thus, radiotherapy departments are aware of SD due to treatment, however, it is unclear who is responsible for discussing sexual function after radiation.

## Interpretation

An apparent need of information material concerning SD after treatment is evidently present among men treated for prostate cancer. The majority of the group of men studied by Crowley et al. (2015) stated that more extensive information concerning sexuality and intimacy issues throughout treatment would have been appreciated. More than half of these men (57%) were anxious whether they would be able to sexually satisfy their partners after treatment, and if these consequences would have an impact on the romantic relationship (46%). Role of partners regarding intimacy and sexuality is hardly mentioned in studied written information material. Nevertheless, partners indeed report an unmet need for information concerning altered intimacy between them and their partner (Adams, Boulton, & Watson, 2009). Partners of men with prostate cancer indicate information regarding sexuality as excessively important (Rees, Sheard, & Echlin, 2003). Furthermore, partners require to be involved in health care issues of their spouses and are willing to participate in sexual health counselling if necessary (Garos et al., 2007).

Prostate cancer treatment and its sexual side effects also affect a partners' quality of life severely (Eisemann, Waldmann, Rohde, & Katalinic, 2014). Moreover, research has found partners to suffer more frequently from depressive symptoms, are often sexually dissatisfied and experience less communication with respect to sexuality with their partner after treatment (Garos et al., 2007).

Sexual side effects are often not addressed by physicians or oncology nurses during follow-up consultations (Hordern & Street, 2007; Krouwel et al., 2015). Moreover, research has shown that patients forget 40% to 80% of the information which is verbally given by physicians or other health care providers during consultation (Kessels, 2003). Accordingly, the essence of written information provision around sexuality during informed consent was reported by 61%



of men with prostate cancer studied by Feldman-Stewart et al. (2000). Thence providing additional information material becomes of great importance. Written information material is the most preferred source of information by patients when it comes to sensitive topics as sexuality and intimacy issues (Davison, Keyes, Elliott, Berkowitz, & Goldenberg, 2004). Physicians are thus more likely to provide written information material such as brochures, guidebooks or useful website addresses along with informed consent. These sources are most frequently used as additional information material concerning information provision around prostate cancer treatment (Ramsey et al., 2009).

## **Clinical implications**

The content of written information material among Dutch urology and radiotherapy departments should be equivalent regarding altered sexuality throughout treatment. Consequently, additional information for partners should be available since it evidently lacks in current information provision. Unfortunately, current written information provision is entirely subjected to whether a hospital or clinic is willing to provide information about altered sexuality throughout prostate cancer treatment. Hence, it is of great importance to provide adequate information for optimal coping with eventual upcoming sexual side effects.

At present, no uniform standard exists stating the most important topics which should be discussed in written information material for men undergoing prostate cancer treatment. Since written information material currently provided does not address sexuality routinely and the impact to the relationship is hardly mentioned, it is highly relevant to assemble a list of standard topics essential to men with prostate cancer and their partners regarding treatment-related SD. Based on our results, a list was established enclosing important matters that need to be discussed (Figure 1). In this respect, by implementing these topics in future patient written information material, men with prostate cancer and their partners could be optimally informed concerning sexual side effects that may emerge after treatment.

Not only can ED treatment options be further specified, but sexual counselling possibilities can be determined as well. Moreover, a uniform standard concerning topics for written information material can help to not only distribute an extensive and comprehensive brochure for men with prostate cancer, but to their partners as well. Specific information for partners can be determined as well as sexual health care possibilities when altered sexuality and impact to the relationship is experienced.

Referral possibilities could be further specified for concerning urology and above all radiotherapy departments, as knowledge regarding sexual health care within corresponding hospital or clinic was not present among many participating departments. Available sexual counselling possibilities should be familiar among departments where men with prostate cancer are treated in order to provide adequate health care. If sexual counselling is not available within the corresponding department, knowledge of referral possibilities elsewhere is of great importance.

- ✓ Mention sexuality in a separate chapter
- ✓ Discuss impact of treatment on erectile function
- ✓ Discuss impact of treatment on ejaculation (if applicable)
- ✓ Discuss etiology of SD and its consequences, both physical as mental aspect
- ✓ Discuss ED treatment possibilities
- ✓ Discuss possible impact of SD to the romantic relationship
- ✓ Involve the partner in context of intimacy and sexuality
- ✓ If possible, provide separate written information material for the partner
- ✓ Mention sexual health care availability within department and/or external location
- ✓ Mention contact details of sexual health care provider (phone number/email address)

**Fig 1.** Recommended checklist regarding the content of written information material provided to men with prostate cancer concerning treatment-related SD.

## Strengths and limitations

One of the main strengths of this study was the high response rate, both in completed questionnaires and received brochures. Almost 70% of all eligible urology and radiotherapy departments participated in this study; so a reasonable impression is obtained when it comes to information provision around sexuality throughout prostate cancer treatment in the Netherlands. Furthermore, all written information material was scored by two individual, objective researchers and in case no agreement was achieved, a third researcher scored written information material and discussed the scores until an agreement was conceived by any means. Hence, objective scoring was performed to prevent bias concerning the analysis of provided written information material.

There are a few limitations to this study that should be discussed. Several hospitals were interviewed by telephone leading to participants doubting about anonymity, although anonymity was guaranteed explicitly. Also, a few participants who already gave permission to participate and questionnaires were sent to, indicated lack of time to complete the questionnaires. Further reasons for not completing the questionnaire could be a lack of knowledge or little affinity concerning sexual health care within corresponding department leading to non-response bias. Besides, it remains uncertain as to which extent the content of brochures from departments which refused to participate in this study varied. In addition, it is possible that the concerning person who completed the questionnaire is better or worse informed when it comes to availability of sexual health care as to other health care professionals coming from the same department. It is rather plausible this contributes to an unreliable reflection of overall knowledge of concerning department leading to information bias. However, several attempts

were made by the researchers to reach the health care professional with sufficient knowledge regarding this subject.

We did not investigate which type of information (i.e. written, E-health, nurse consultation, etc.) or which specific content regarding sexuality is considered to be important by patients. Consequently, future research is recommended concerning information needs from the patients' point of view. Accordingly, the content of information material concerning sexuality after prostate cancer treatment can be adjusted to the needs of patients and their partners.

## CONCLUSION

Treatment-related SD is not routinely mentioned in written information material provided by Dutch urology and radiotherapy departments. Little information is available concerning the patient's partner in context of intimacy and sexual health. No information was available regarding the impact of SD on the romantic relationship between patient and partner.

Consequently, it is recommended to establish a standard regarding the content of written information material in order to provide material of high-quality, extensive and comprehensive information.

Sexual health care is not available at every hospital or clinic where prostate cancer is treated. Furthermore, radiotherapy departments spent less attention to sexual side effects. Hence, it is recommended for radiotherapy departments to enhance their awareness of detecting sexual health issues and subsequently, increase their knowledge regarding sexual counselling referral possibilities.

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# PART II

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Discussion of fertility concerns with cancer  
patients of reproductive age

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# Chapter 9

*Fertility preservation counselling in Dutch Oncology  
Practice: Are nurses ready to assist physicians?*

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## INTRODUCTION

In the Netherlands, approximately one in ten cancer diagnoses concerns an adult of reproductive age (Dutch Cancer Registration 2015). Cancer survivors in this age group have reported that the effect of treatment on their fertility is one of their greatest concerns (Schover, 2005); decreased childbearing ability is a cause of long-term distress (Carter et al., 2010; Green, Galvin, & Horne, 2003; Lee et al., 2006; Partridge et al., 2004; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Whether impaired fertility due to gonadotoxic treatment will occur cannot be accurately predicted; it depends on a number of factors. Primary causes are alkylating agents and whole body irradiation, depending on treatment dose, sex and age, site of cancer and stage of disease (Jeruss & Woodruff, 2009; Lee et al., 2006; Wallace, Anderson, & Irvine, 2005). Pelvic surgery may also lead to damage or loss of reproductive organs. Moreover, hormonal changes (e.g. due to cranial irradiation damaging the pituitary axis) or treatments may have effects on reproductive organs (Ruddy & Partridge, 2012).

With increasing survival rates due to early detection and advances in medical treatment, quality of life becomes progressively important, including future reproductive potential. Discussing fertility should be a pressing priority for oncology health care providers immediately after diagnosis, since direct action or modification of therapy may be required. Fertility preservation (FP) is an opportunity to secure future reproductive ability, provided a patient meets the eligibility criteria. Given the number of survivors who have undergone cancer treatment before or during childbearing age, FP is considered greatly beneficial. For women, ovarian transposition and cryopreservation of embryo and oocytes are the established methods of FP (American College of Obstetricians and Gynecologists 2014; Lobo, 2005; Redig, Brannigan, Stryker, Woodruff, & Jeruss, 2011; Sonmezer & Oktay, 2004). The male option is sperm cryopreservation, with various sperm isolation procedures depending on ejaculation status (Trost & Brannigan, 2012). Other innovative possibilities are being developed: cryopreservation of ovarian tissue and cryopreservation of testicular tissue. These methods are, however, still experimental and not yet widely available (Chian et al., 2009; Practice Committee of American Society for Reproductive Medicine 2014; Yokonishi et al., 2014). In the Netherlands, the currently available methods include ovarian transposition (standard), cryopreservation of embryos (standard), ovarian tissue (experimental) and oocytes (experimental) (Garvelink, Ter Kuile, Hilders, Stiggelbout, & Louwe, 2013), and cryopreservation of sperm (standard) and testicular tissue (experimental). As yet, there are no reports of current success rates of female options in the Netherlands. Sperm cryopreservation success rates have been investigated—in a study performed in 898 Dutch men who had had cancer, 10.7% made use of their preserved sperm, with a success rate (defined as parenthood) of 77% (Muller, Oude Ophuis, Broekmans, & Lock, 2014).

Despite its wide availability, several studies have reported that FP is not addressed routinely nor in detail by oncology health care providers (Armund et al., 2012; Bastings, Baysal, Beer-

endonk, Braat, & Nelen, 2014; King et al., 2008; Quinn et al., 2007, 2009; Schover, Rybicki, Martin, & Bringelsen, 1999; Schover et al., 2002; Vadaparampil et al., 2007; Yee, Abrol, McDonald, Tonelli, & Liu, 2012). Patients do not recall a conversation about FP with their oncologists and report not being offered the opportunity of FP (Nakayama et al., 2009; Schover et al., 1999, 2002; Thewes et al., 2005; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). A recent study from a university hospital in the Netherlands by Bastings et al., 2014, reported that only 9.8% of all newly diagnosed female cancer patients aged 0–39 years were referred for FP counselling. The American Society of Clinical Oncology and the American Society for Reproductive Medicine guidelines recommend that oncologists should discuss infertility risks and FP with their cancer patients prior to commencement of cancer treatment (Ethics Committee of the American Society for Reproductive Medicine 2005; Loren et al., 2013). Similarly, the Dutch Oncology Society has developed guidelines for female (Werkgroep Oncologische Gynaecologie (WOG) 2009) and male patients (IKR-projectgroep Cryopreservatie van zaadcellen 2010), highlighting the responsibility and the importance of oncology health care providers providing adequate counselling about FP. Nonetheless, the implementation of these guidelines in clinical practice is unclear. Although FP, just like any potential treatment risk, should be discussed, there are several reasons why this is challenging for oncologists (Duffy, Allen, Dube, & Dickersin, 2012; Gilbert, Adams, Mehanna, Harrison, & Hartshorne, 2011; Louwe et al., 2013; Quinn et al., 2009). A major barrier is the often limited time to go into detail about the diagnosis and the treatment plan as related to psychosocial concerns (Adams, Hill, & Watson, 2013). Other factors which may influence whether fertility options are discussed include prognosis, the patients' age, a need for immediate therapy, hormonal receptor expression, whether the patient already has a child, the patient not having a partner, the costs, poor success rates of FP and limited knowledge about FP options (Adams et al., 2013; Arafa & Rabah, 2011; Forman, Anders, & Behera, 2010; King, Davies, Roche, Abraham, & Jones, 2012; Louwe et al., 2013).

The issue of lack of time may be addressed by involving other health care professionals in the discussion of fertility concerns (Gilbert et al., 2011), particularly oncology nurses who may serve as a link between oncologists and patients. According to a survey among 201 cancer survivors, the oncology nurse was the second-most likely person to initiate discussion on FP besides the oncology physician (Schover et al., 2002). A Dutch study with oncology nurses and oncologists found similar results (Garvelink, Ter Kuile, Louwe, Hilders, & Stiggelbout, 2012).

With the aim of ensuring that all patients receive FP information at the appropriate time, it is suggested that oncology nurses might be suitable care providers to initiate discussions about FP, provide information and facilitate the referral. The objective of this study was to explore the oncology nurses' role by investigating their knowledge about FP, how they apply this in practice, their feeling of responsibility to discussing fertility concerns with patients of reproductive age facing cancer, as well as any barriers they encounter.

## METHODS

### Study design

A cross-sectional, anonymous survey was performed using a newly designed questionnaire. The study sample involved Dutch oncology nurses from various departments, hospitals, specialisations and regions across the country.

### Questionnaire design

As a validated questionnaire for assessing the provision of FP counselling among oncology nurses does not yet exist, a measuring instrument was designed by the author in collaboration with an expert team consisting of a urologist-sexologist, a professor of oncology, an oncology research nurse and an experienced quantitative researcher. Topics were identified from current practice and in the literature (Adams et al., 2013; Forman et al., 2010; King et al., 2008; Louwe et al., 2013). The 21-item questionnaire contains a demographic sheet and Likert-scale items (ranging from 1 = *never/rarely* to 5 = *often/always*) measuring practices and knowledge regarding FP and sexual functioning, as well as barriers to and responsibility for addressing these issues. Data concerning sexual functioning were processed separately (Krouwel et al., 2015). In a pilot study, the questionnaire was reviewed by a panel consisting of 10 randomly chosen oncology nurses (anonymous to the authors) from the Leiden University Medical Centre. The panel tested the questionnaire for its validity at face value; it was modified on the basis of their feedback.

### Survey procedure

The online questionnaire was e-mailed to all oncology nursing departments throughout the Netherlands with the request to distribute it amongst all employed oncology nurses. Furthermore, the survey was promoted at online Dutch oncology nursing platforms, including the website and newsletter of the Dutch Oncology Nursing Society, social media groups (LinkedIn and Facebook) of the Dutch Oncology Nursing Society and the website “www.nursing.nl.” At the Dutch Annual Oncology Nursing Congress in November 2012, several volunteers approached the oncology nurses who were attending and asked them to complete the questionnaire. Nurses who had already participated in the online survey did not receive a copy. As a form of appreciation, books concerning cancer and sexuality were provided to each nurse who participated during the Congress. Data were collected from September 2012 to December 2012. Data from the web-based survey and the congress survey were processed together.

### Statistical analysis

Analysis was performed using SPSS Release 20 (SPSS, Chicago, IL). The 10 responses from the pilot survey were added to the final analysis group, because all questions were completed by the nurses in the pilot survey and only small modifications have been made to the final instru-

ment. The sample was split by gender, age (set at median age: 44 years or under vs. over 44), experience (0–10 years vs. 11 or more) and grade (graduate nurses vs. other grades) to examine if gender, seniority and years in service had a bearing on oncology nurses' knowledge and practice patterns regarding FP. The practice patterns in discussing fertility issues were adapted for calculation; results in the response category "never/hardly ever" formed one category; the responses "in less than half of the cases," "in half of the cases" and "in more than half of the cases" were merged into one category: "in a medial number of cases," while "almost always/always" remained one category. The oncology nurses were given a list of possible barriers to discussing FP and asked to indicate the extent to which they agreed.

Descriptive statistics and frequency distribution were calculated for all variables. Chi-squared tests and Cochran-Armitage test for trend were used to look for associations between categorical variables and demographic characteristics;  $p < .05$  two-sided were considered statistically significant.

## Ethics

In the Netherlands, research that does not involve either patients or interventions is not subject to formal approval from ethical boards. In previous research amongst nurses, the Medical Ethics Committee was consulted and declared that no formal ethical approval was needed (Bekker, van Driel, Pelger, Nijeholt, & Elzevier, 2011). The study was approved by the scientific committee of the Urology Department of the LUMC. Information about the study was provided to potential participants; the aims and anonymity of the survey were highlighted. Participation in the survey was completely voluntary; informed consent was obtained from all individual participants included in the study. An opt-out possibility was offered. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

## RESULTS

### Participants

A total of 615 oncology nurses logged in to the questionnaire or demonstrated an interest in participating at the Congress. The number who completed the questionnaire was 421: 10 were recruited for the pilot survey, 283 through the Internet and 128 at the congress. The sample consisted of Dutch nurses involved with cancer patients working in various departments in several clinical settings, as defined in Table 1.

**Table 1.** Demographic characteristics

<b>Demographic characteristics (n=421)</b>	<b>n (%)</b>
<b>Age (years)</b>	405 (96.2)
Mean 42.6 years	
Median 44 years (range 21-62)	
Unknown	16 (3.8)
<b>Gender</b>	
Male	23 (5.5)
Female	385 (91.4)
Unknown	13 (3.1)
<b>Oncology experience (years)</b>	
<1	8 (1.9)
1–2	25 (5.9)
3–5	81 (19.2)
6–10	75 (17.8)
11–15	82 (19.5)
>15	137 (32.5)
Unknown	13 (3.1)
<b>Employment setting</b>	
Registered nurse <sup>a</sup>	71 (16.9)
Registered nurse currently in Oncology registration training	18 (4.3)
Registered nurse with Oncology certificate <sup>b</sup>	189 (44.9)
<i>Clinical setting</i>	
• In-patient	79 (18.8)
• Out-patient department	93 (22.1)
• In/out-patient	17 (4.0)
Registered nurse with graduate degree <sup>c</sup>	101 (24.0)
Nurse in charge of Oncology Department <sup>d</sup>	7 (1.7)
Research nurse	7 (1.7)
District nurse with Oncology specialism <sup>e</sup>	8 (1.9)
Different/unknown	20 (4.8)
<b>Hospital type</b>	
University hospital	148 (35.2)
District teaching hospital	124 (29.5)
District hospital	126 (29.9)
Extramural	8 (1.9)
Unknown	15 (3.6)
<b>Area of specialization<sup>f</sup></b>	
• Single area of specialization	168 (39.9)
• Multiple areas of specialization	236 (56.1)
• Unknown	17 (4)
 Breast	 221 (52.5)
Colorectal	212 (50.4)
Gynaecology	166 (39.4)



**Table 1.** Demographic characteristics (*continued*)

Demographic characteristics ( <i>n</i> =421)	<i>n</i> (%)
Lung	149 (35.4)
Haematology	149 (35.4)
Nephro- and urology	140 (33.3)
Lymphoma	123 (29.2)
Head and neck	90 (21.4)
Skin	76 (18.1)
Sarcoma	64 (15.2)
Neuro-endocrine	48 (11.4)
Unknown	17 (4)

<sup>a</sup> Vocational trained nurses as well as bachelor's degree nurses with no registered specialism but currently employed in an Oncology Department.

<sup>b</sup> Nurses with official Oncology registration (acknowledged by the Dutch board of Hospital Education) following 1 year official Oncology training.

<sup>c</sup> Nurses with a Master's degree from a University or Higher Education College, usually involved with in- and outpatient departments.

<sup>d</sup> Clinical setting undefined.

<sup>e</sup> Nurses caring for cancer patients at home.

<sup>f</sup> Multiple areas of specialisation possible.

## Practice behaviour

In response to the question “How often do you discuss fertility issues with patients of reproductive age?,” answers ranged from: “never/hardly ever” (27.7%), “in less than half of the cases” (21.2%), “in half of the cases” (8.4%), “in more than half of the cases” (10.5%) to “almost always/always” (32.2%) (*n* = 419). The frequency of discussing fertility issues was associated with having a Master degree, experience, knowledge related to FP and some specialisations (Table 2).

## Perceived knowledge of FP

When it comes to knowledge of FP options, 31.1% of the nurses reported having “sufficient” or “a lot” of knowledge. Others declared having “some” (39.7%), “not so much” (23.3%) and “no” knowledge (5.2%) about FP (*n* = 418). Calculated associations with age, gender, experience in the field of oncology nursing, Master's grade and specialisation in relation to perceived knowledge are presented in Table 3.

**Table 2.** Demographic factors and specialisations in relation to the frequency of discussing FP

Demographic item	FP never / hardly ever discussed	FP discussed in moderate number of cases	FP almost always / always discussed	<i>P</i> <sup>a</sup>
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Total	116 (27.7)	168 (40.1)	135 (32.2)	
Gender				
Male	9 (39.1)	7 (30.2)	7 (30.4)	NS
Female	104 (27.2)	156 (40.7)	123 (32.1)	
Age				
44 years and under	56 (27.6)	85 (41.9)	62 (30.5)	NS
Over 44 years	60 (28)	83 (38.8)	71 (33.2)	
Master's grade				
Master's degree	22 (22)	30 (30)	48 (48)	.001
Non-academic training	91 (29.7)	133 (43.5)	82 (26.8)	
Oncology experience				
≤10 years of experience	71 (37.6)	70 (37)	48 (25.4)	<.001
>11 years of experience	42 (19.4)	93 (42.9)	82 (37.8)	
Hospital setting				
University hospital	26 (17.6)	62 (41.9)	60 (40.5)	<.001
Non-academic hospital	86 (33.7)	99 (38.8)	70 (27.5)	
Perceived knowledge about FP				
Sufficient knowledge	6 (4.6)	41 (31.5)	83 (63.8)	<.001
Insufficient knowledge	110 (38.2)	126 (43.8)	52 (18.1)	
Area of specialization <sup>b</sup>				
Breast +	53 (24)	95 (43)	73 (33)	NS
Breast -	59 (32.6)	66 (36.5)	56 (30.9)	
Colorectal +	63 (29.7)	95 (44.8)	54 (25.5)	.020
Colorectal -	49 (25.8)	66 (34.7)	75 (39.5)	
Haematology +	32 (21.5)	60 (40.3)	57 (38.3)	.013
Haematology -	80 (31.6)	101 (39.9)	72 (28.5)	
Lymphoma +	25 (20.3)	53 (43.1)	45 (36.6)	.039
Lymphoma -	87 (31.2)	108 (38.7)	84 (30.1)	
Lung +	49 (33.1)	63 (42.6)	36 (24.3)	.010
Lung -	63 (24.8)	98 (38.6)	93 (36.6)	
Urology +	32 (23.2)	69 (50)	37 (26.8)	NS
Urology -	80 (30.3)	92 (34.8)	92 (34.8)	
Gynaecology +	40 (24.2)	82 (49.7)	43 (26.1)	NS
Gynaecology -	72 (30.4)	79 (33.3)	86 (36.3)	
Dermatology +	21 (28)	38 (50.7)	16 (21.3)	NS
Dermatology -	91 (27.8)	123 (37.6)	113 (34.6)	

**Table 2.** Demographic factors and specialisations in relation to the frequency of discussing FP (*continued*)

Demographic item	FP never / hardly ever discussed	FP discussed in moderate number of cases	FP almost always / always discussed	<i>P</i> <sup>a</sup>
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Total	116 (27.7)	168 (40.1)	135 (32.2)	
Head- and neck +	29 (32.6)	40 (44.9)	20 (22.5)	.048
Head- and neck -	83 (26.5)	121 (38.7)	109 (34.8)	
Neuro-endocrine +	11 (23.4)	26 (55.3)	10 (21.3)	NS
Neuro-endocrine -	101 (28.5)	135 (38)	119 (33.5)	
Sarcoma +	14 (22.2)	34 (54)	15 (23.8)	NS
Sarcoma -	98 (28.9)	127 (37.5)	114 (33.6)	
Multiple specialties	64 (27.1)	103 (43.6)	69 (29.2)	NS
Single specialty	48 (28.9)	58 (34.9)	60 (36.1)	

Abbreviation: NS, not significant. NA, not applicable.

a) *P* value of linear-by-linear association between frequency of discussing FP and demographic items.

b) Many nurses reported multiple specializations, as shown in Table 1. Plus (+) indicates that this group reported the area as a speciality; minus (-) indicates they did not report this area as a speciality.

**Table 3.** Demographic factors and specialisations in relation to the perceived knowledge about FP

Demographic item	Sufficient perceived knowledge	Limited perceived knowledge	<i>P</i> <sup>a</sup>
	<i>n</i> (%)	<i>n</i> (%)	
Total:	127 (31.4)	278 (68.6)	
Gender			
Male	6 (26.1)	17 (73.9)	NS
Female	121 (31.7)	261 (68.3)	
Age			
44 years and under	58 (28.7)	144 (71.3)	NS
Over 44 years	73 (34.1)	141 (65.9)	
Master's grade			
Master's degree	51 (51.0)	49 (49.0)	<.001
Non-graduate	76 (24.9)	229 (75.1)	
Oncology experience			
≤10 years of experience	39 (20.7)	149 (79.3)	<.001
>11 years of experience	88 (40.6)	129 (59.4)	
Hospital setting			
University hospital	54 (36.5)	94 (63.5)	NS
Non-academic hospital	72 (28.3)	182 (71.7)	
Area of specialization <sup>b</sup>			
Breast +	73 (33.2)	147 (66.8)	NS
Breast -	53 (29.3)	128 (70.7)	

**Table 3.** Demographic factors and specialisations in relation to the perceived knowledge about FP (*continued*)

Demographic item	Sufficient perceived knowledge	Limited perceived knowledge	<i>P</i> <sup>a</sup>
	<i>n</i> (%)	<i>n</i> (%)	
Total:	127 (31.4)	278 (68.6)	
Colorectal +	53 (25.1)	158 (74.9)	.004
Colorectal -	73 (38.4)	117 (61.6)	
Haematology +	52 (35.1)	96 (64.9)	NS
Haematology -	74 (29.2)	179 (70.8)	
Lymphoma +	45 (36.6)	78 (63.4)	NS
Lymphoma -	81 (29.1)	197 (70.9)	
Lung +	38 (25.7)	110 (74.3)	NS
Lung -	88 (34.8)	165 (65.2)	
Urology +	42 (30.2)	97 (69.8)	NS
Urology -	84 (32.1)	178 (67.9)	
Gynaecology +	49 (29.7)	116 (70.3)	NS
Gynaecology -	77 (32.6)	159 (67.4)	
Dermatology +	20 (26.7)	55 (73.3)	NS
Dermatology -	106 (32.5)	220 (67.5)	
Head- and neck +	20 (22.2)	70 (77.8)	.033
Head- and neck -	106 (34.1)	205 (65.9)	
Neuro-endocrine +	16 (33.3)	32 (66.7)	NS
Neuro-endocrine -	110 (31.2)	243 (68.8)	
Sarcoma +	18 (28.1)	46 (71.9)	NS
Sarcoma -	108 (32.0)	229 (68.0)	

Abbreviation: NS, not significant. NA, not applicable.

a) *P* value of chi-squared test between level of knowledge about FP and demographic items

b) Many nurses reported multiple specializations, as shown in Table 1. Plus (+) indicates that this group reported the area as a speciality; minus (-) indicates they did not report this area as speciality.

## Barriers

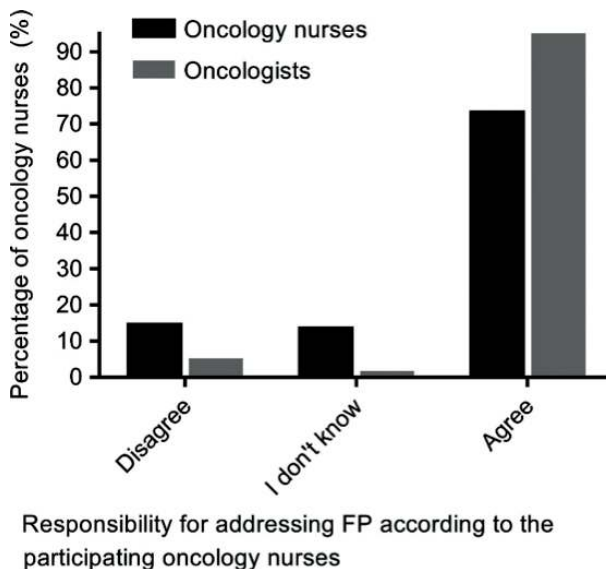
The most important reasons for not discussing FP options were a “lack of knowledge” (25.2%), “a poor prognosis” (16.4%) and “lack of time during a consultation” (10.5%). All barriers and the percentages of nurses agreeing and disagreeing are presented in Table 4.

**Table 4.** Barriers to discussing fertility preservation

I would tend not to discuss fertility preservation with a patient because:	(Strongly) Agree	Neither agree nor disagree	(Strongly) Disagree
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
of lack of knowledge about FP	104 (25.2)	111 (26.9)	198 (47.9)
the patient has a poor prognosis	67 (16.4)	116 (28.4)	225 (55.2)
of lack of time during a consultation	43 (10.5)	81 (19.8)	286 (69.6)
the patient does not ask about it	29 (7.1)	74 (18.0)	307 (74.9)
the patient is 40 years of age or older	29 (7.0)	61 (14.8)	322 (78.2)
it might raise concerns for the patient and their family or spouse	26 (6.3)	72 (17.5)	313 (76.2)
curing has a greater priority	23 (5.6)	67 (16.3)	320 (78.1)
the patient is currently not in a relationship	20 (4.9)	62 (15.0)	330 (80.1)
I do not know where to refer the patient to	20 (4.9)	59 (14.4)	331 (80.7)
the patient already has children	9 (2.2)	44 (10.7)	358 (87.1)

## Responsibility

Almost all nurses considered the oncologists to be responsible for discussing FP (94.5%). A majority felt the oncology nurses be responsible (72.8%), 13.1% did not know if they should feel responsible and 14.1% did not feel responsible for discussing FP. The level of agreement from the responders on responsibility of the oncology nurses vs. the oncologists is illustrated in Figure 1.



**Fig 1.** Answers to the questions: “Should the oncologist carry responsibility for addressing fertility preservation?” and “Should the oncology nurse carry responsibility for addressing fertility preservation?” (*n* = 419)

## DISCUSSION

### Summary

This study reports on the attitudes, knowledge and feeling of responsibility of oncology nurses with regard to discussing FP. Graduate nurses and experienced nurses reported having more knowledge of the subject, and, together with nurses working in a university hospital, were more likely to discuss the issue with the patient. In general, an optimistic picture emerges for the role of oncology nurses in assisting with the discussion of FP, as the majority of them feel responsible for addressing the issue. This role could be enhanced if their level of knowledge about the subject is improved and attention is paid to the importance of ensuring that information about FP options is routinely provided to patients.

### Comparison with existing literature

Considering the number of studies on the attitude of oncologists (Duffy et al., 2012; Forman et al., 2010; Quinn et al., 2009), the role of oncology nurses in the discussion of FP is relatively unexplored. There has been an American qualitative pilot-study (King et al., 2008), and a survey from the United States focusing on oncology nurses' knowledge of survivorship, which found that less than 25% of their sample reported having knowledge of fertility issues (Lester, Wessels, & Jung, 2014). Australian nurses reported being least confident about discussing fertility with patients. Consequently, this was one of the least-performed interventions during survivorship care (Wallace et al., 2015). A survey focusing on the discussion of sexuality by oncology nurses reported that 60% of their sample had perceived knowledge on fertility and 67% felt comfortable discussing fertility with patients (Moore, Higgins, & Sharek, 2013). There are also, several studies on practice patterns of paediatric nurses (Clayton et al., 2008; Vadaparampil et al., 2007).

The qualitative, single-centre survey performed in the United States, addressed oncology nurses' knowledge and attitudes to discussing FP with non-paediatric patients (King et al., 2008). Outcomes are comparable to those of our survey with only half of the nurses actually discussing FP methods with their patients, although most believed this to be part of their role (King et al., 2008). Similar to our findings, level of knowledge, time constraints and patient characteristics were mentioned as barriers. Some nurses participating in King et al.'s survey believed that the physician should initiate the FP discussion and let the nurse provide the follow-up care.

This study results indicate that the vast majority of the nurses consider addressing FP to be their task; practically all nurses consider it a task for the oncologists. The division of tasks might, however, be more subtle, as suggested by Garvelink et al. (2012). There is a difference between bringing up the subject and actually discussing FP options; a different individual could be responsible for each task. Every eligible patient should at least receive some informa-

tion about FP shortly after diagnosis. This could be provided by an oncology nurse, followed later by detailed information from a fertility expert.

In the Netherlands, the majority of FP clinics for female cancer patients are located in university hospitals, an interesting fact considering the difference in frequency of discussing FP between academic and non-academic nurses, especially as no difference in knowledge was reported. Apparently, the possibility of being able to refer a patient to a local fertility specialist increases the comfort in discussing fertility concerns. This phenomenon was also shown by a physician survey: the oncologists reported that the offer of FP was influenced by its local availability (Louwe et al., 2013). On the contrary, in the UK, 63% of the surveyed oncologists reported that the availability of fertility services is not a factor (Adams et al., 2013).

A complementary research topic is whether nurses' moral considerations can legitimately exert an influence when offering or withholding the discussion of FP. Such issues should not prevent patients from protecting their future ability to have a biological child, a view confirmed by a consensus among Dutch clinicians: personal opinions of clinicians as well as the hospital's general view should not influence the provision of information about FP (Garvelink et al., 2012). Every patient—whatever their condition, prognosis, family status or age—should at least be informed about the consequences of the treatment with regard to fertility impairment. Moral considerations due, for example, to religious or other beliefs, might, however, mean that not every healthcare provider is able to discuss this delicate subject. Possible reasons for withholding discussion on fertility issues and referral for FP are a delay in starting treatment, which in certain situations would not be advisable, and a poor prognosis. However, as the posthumous use of preserved material is legally accepted in the Netherlands, a poor prognosis should not be a reason for withholding information (Kalkman-Bogerd, Hendriks, & Egberts, 2006).

## Strengths and limitations

As the recruitment procedure used a web-based survey and a personal approach during an oncology nursing congress, a response rate cannot be calculated. The results might represent an underestimation of practices due to a non-response bias, as oncology nurses with no affinity with the subject of FP may not have been motivated to participate. On the other hand, the survey method relies on self-report, which may have led to an overestimation of practices. Self-perceived knowledge rather than objective knowledge was measured. Although no validated instrument exists for assessing the discussion of FP by oncology nurses, serious attempts were made to develop an adequate, pilot-tested measuring instrument in the form of this questionnaire. The sample was restricted to a national Dutch setting. Although differences in culture and medical guidelines could affect the provision of FP counselling by oncology nurses, the comparative findings derived in a qualitative study from the US suggest that the results may be applicable in other Western countries (King et al., 2008).

## The importance of FP counselling

Future parenthood is of considerable importance to survivors of cancer (Yee et al., 2012; Zebrack et al., 2004). Generally, 75% of patients of reproductive age diagnosed with cancer wish to have a biological child in the future (Schover et al., 1999) and according to Schover et al. (2002), 24% of childless men felt that having cancer had increased their wish to have children.

Currently, it is estimated that a reproductive specialist sees only 9.8%–61% of young women before they undergo cancer treatment (Bastings et al., 2014; Letourneau et al., 2012). About one-third of a group of young female cancer patients indicated that the discussion of fertility concerns was initiated by themselves, their friends or family rather than their health care providers (Yee et al., 2012). In Partridge's et al. (2004) paper, 29% of women reported that the fear of becoming infertile influenced their treatment decisions. As for young male patients, 51% had been offered sperm banking and 60% recalled being informed about infertility as a side-effect of cancer treatment (Schover et al., 2002). Evidence suggests that patients who were not informed about FP at the time of treatment initiation, might be angry and disappointed (Zebrack et al., 2004). It is, therefore, important to consider the effect of any proposed therapy, as well as which strategies exist to protect or restore fertility in later life.

The Dutch guideline on FP for male cancer patients specifically describes the role of the oncology nurse: if the medical history does not report a discussion on FP, the nurse is supposed to bring this to the attention of the physician (IKR-projectgroep Cryopreservatie van zaadcellen 2010). The practice of oncology nursing encompasses the roles of direct caregiver, educator and consultant and as oncology nurses interact more directly with patients and their families, they are in an excellent position to discuss FP and guide them to finding more information.

## Implications for clinical practice

In the United States, an “onco-fertility” consortium is making significant attempts to overcome the lack of interface between clinicians in the field of oncology and fertility. In the Netherlands, there is a similar network on FP (Nederlands Netwerk Fertiliteitspreservatie). Collaboration within this type of network can facilitate education, improvement of guidelines and referral lists. A coordinated approach and more systematic infrastructures contribute to enhancement of availability of FP for all young cancer patients. Until there is an infrastructure for referral for FP which can be implemented in young oncology patients, we recommend that every oncology team appoints an individual who is confident to discuss these matters of responsibility for coordinating fertility counselling. A nurse or a nurse specialist is in a suitable position to take this responsibility and to check whether or not an FP discussion has taken place. Documenting the status of fertility discussions could reinforce the cooperation and interaction between doctors and nurses. Specific nursing guidelines concerning FP could be developed, clarifying how to deal with this issue and providing background information about FP options. Information sources for patients should become more widespread, referral lists easy to access, and should include contact information for both female and male patients.



In conclusion, less than half of oncology nurses are comfortable discussing fertility issues. The vast majority report limited knowledge about FP options, but do feel responsible for addressing FP, in cooperation with the oncologist. There is room for enhancing the practical role of oncology nurses in assisting with FP discussions and documentation; also, education aimed at facilitating FP discussions by nurses with patients should be extended or incorporated. Clinical practice guidelines could be accentuated, specifying the role of the nurse and the need to document discussions about referral for FP. Future studies should focus on the division of tasks within oncology departments and on the implementation of structured programmes ensuring FP issues are addressed at all times.

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# Chapter 10

*An Educational Need regarding Treatment-related Infertility and Fertility Preservation; A National Survey among Members of the Dutch Society for Medical Oncologists*

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## INTRODUCTION

Cancer treatments are associated with a variety of undesirable side effects; of which one of specific concern to young men and women is the effect on their endocrine health and future reproductive ability [38]. Due to the increasing 5-year, and overall survival over the past few decades, consideration for physical and psychological consequences becomes progressively prioritized [11]. Loss of fertility is a devastating side effect for young cancer survivors with severe emotional impact [2], and specifically resulting from treatment with chemotherapy or radiation therapy [16, 27, 32]. Moreover, the prospect of facing treatment-induced infertility for women of reproductive age is proven to affect their cancer treatment decisions in up to 41% [22, 34].

Cytostatic cancer drugs are designed to target dividing cells; implying that in addition to inhibiting cancer cell growth, proliferating primordial follicles which enfold oocytes are conjointly harmed [6]. As for men, infertility and persistent azoospermia is a common long-term adverse effect [7]. Alkylating drugs are feared most for their effect to fertility, by inducing both impaired fertility and early menopause [33]. Although the exact risk for cancer- and treatment related infertility depends on the chemotherapy agent, the chemotherapeutic regime and the age of the patient, it should not be underestimated considering the long-term impact. Being the physician prescribing cytostatic drugs, the medical oncologist is responsible for informing about the risk of infertility before commencing a gonad toxic treatment, referral to a reproductive specialist for fertility preservation (FP) and discussing alternative treatment strategies if applicable. Nonetheless, various studies suggest the information provision regarding fertility issues is often experienced as inadequate by patients. Furthermore, it is suggested that cancer care physicians do not possess sufficient knowledge regarding fertility risks and options for FP [36, 25, 8, 13]. As a result, information is not timely provided or in some cases is not provided at all [3, 4, 23]. At the time of diagnosis, fertility issues are often outweighed by the focus on survival. A Dutch observational study, showed in 2011, a total of 9.8% of female patients were referred for FP counselling. However, the absolute numbers of patients receiving FP counselling increased over time [5]. And indeed, informing cancer patients of reproductive age about possible reduced fertility and referral to a reproductive specialist in a timely manner is recommended by national [18, 29], European [31] and international guidelines [24]. Fertility counselling performed by a fertility specialist prior to cancer treatment, in comparison to the oncologist alone, is associated with better psychological health. Those patients who undertook counselling and proceeded with FP reported reduced regret, compared with those who did not proceed to FP [22]. Patients who felt fertility concerns have not been given full consideration at the time of diagnosis have been shown to cope with psychological distress, expressed by uncertainty and concern, as well as higher levels of depression and cancer or fertility-related trauma during survivorship [22].

Over the last decade, we have experienced a surge of scientific reports on aspects of altered fertility in young adults with cancer; these particularly include the growing number of available preservation options [1] and the devastating impact of the loss of fertility to cancer survivors



[9, 30, 37]. In addition, various studies investigated practice regarding (referral for) FP counselling by physicians involved with oncology patients. An overview of quantitative studies among oncology care providers published in the past ten years regarding knowledge level, the discussion of fertility, referral to fertility specialists and barriers regarding this discussion is provided in Supplement 1. Pediatric studies have been excluded in this overview.

To date, published quantitative surveys have suggested there may be a deficiency in medical oncologists' knowledge about FP options and that the provision of information to patients about FP may be suboptimal. The purpose of the hereby presented nationwide study was to evaluate Dutch medical oncologists' practice patterns, knowledge, educational need, attitudes and barriers regarding treatment-related infertility and FP among men and women of reproductive age.

## METHODS

### Study design and cohort identification

A questionnaire was used for collecting data in a cross-sectional postal survey. The sample consisted of 433 members of the NVMO (Dutch Society for Medical Oncology) with several areas of expertise. Our sampling strategy aimed for representation with regard to different tumors, employment setting, level of education, years of oncology experience, type of hospital, age and gender.

### Instrument design and development

The questionnaire was developed by the authors. The content of the questionnaire was evaluated by 4 oncologists working in Leiden University Medical Center through an anonymous pilot study and modified using their feedback. The final version comprised a demographic sheet, including professional background, experience in oncology practice, gender and age. Furthermore, Likert-scale items measured practices, attitudes, content of sexual and fertility counselling, responsibility, need for education and barriers regarding the discussing of sexual function and fertility issues. In addition, a list was made of most common medications measuring knowledge about their possible side effects to sexual function, to future reproductive ability and regarding teratogenicity. Data concerning the discussing of sexuality issues and knowledge about medication were processed separately [19].

### Survey administration

The questionnaires were sent to all medical oncologists who were member of the NVMO, members not practicing in the Netherlands have been excluded. After the initial mailing was finished, reminders were sent to non-responders after 6 and 12 months. An information letter concerning the study and a post-paid return envelope were added, as well as an opt-out possibility. Data were collected anonymously in order to prevent a self-reporting bias.

**Supplement 1.** Overview of quantitative surveys among care providers regarding knowledge, practice, referral and barriers about the discussing of fertility and FP with cancer patients of childbearing age; 1) conducted/published in the past 10 years, 2) excluding qualitative studies and studies concerning pediatric care providers.

Study	Year of survey	Country	Study population	Type of care providers	Eligible participants	Final participants	Completion rate (%) <sub>a</sub>	Female (a) and male (b) patients	Knowledge of FP (%)	Discussing fertility and referral (%) <sub>b</sub>	Two most mentioned barriers (%)
Krouwel <i>et al.</i> [current survey, 2021]	2013-2014	The Netherlands	Dutch Society for Medical Oncology	Medical oncologists	392	120	30.6%	a, b	47.5% sufficient knowledge 76% wants to improve knowledge	Discussing fertility: 68.3% often/always. Referral: 44.6% men, 28.9% women	Prognosis is poor 53%, unlikely patient will survive 43.1%
Vesali <i>et al.</i> [49]	2015-2016	Iran	Attendees congresses	Radiation oncologists and hematologists	131	103	78.6%	a, b	Knowledge GnRH/sperm cryopreservation 2.77 and 2.64	Information provision FP 13.6%. Referral 71.8%.	N.A.
Post <i>et al.</i> [38]	2016	United States	Nationwide	Radiation Oncologists	N.A.	352	N.A.	b	N.A.	Fertility counselling always recommended by 52%	N.A.
Sallem <i>et al.</i> [44]	2012-2013	France	Nationwide	Oncologists	N.A.	102	N.A.	a, b	14% knowledgeable regarding FP	Discussing fertility by 46%, referral 22%	Poor prognosis 54%, urgent treatment 51%
Melo <i>et al.</i> [33]	2013-2015	Portugal	Clinical institutions, Portuguese Oncology Society	Doctors who assist female cancer patients	N.A.	111	N.A.	a	N.A.	Fertility risks discussed 65.7%, preservation 59.3%. Referral 7.38%.	Time, knowledge.
Louwe <i>et al.</i> [30]	Unknown	The Netherlands	Seven of eight regions (85% of the country).	Hematologists, oncologists, radiotherapists, surgeons, gynecologists	406	280	69%	a	Knowledge treatment effect 55-68% chemotherapy 55%, radiation 68%. FP knowledge 13-36%.	79% usually or always discuss fertility issues.	Lack of available reproductive specialists 11%, insufficient time 10%

**Supplement 1.** Overview of quantitative surveys among care providers regarding knowledge, practice, referral and barriers about the discussing of fertility and FP with cancer patients of childbearing age; 1) conducted/published in the past 10 years, 2) excluding qualitative studies and studies concerning pediatric care providers. (*continued*)

Study	Year of survey	Country	Study population	Type of care providers	Eligible participants	Final participants	Completion rate (%) <sub>a</sub>	Female (a) and male (b) patients	Knowledge of FP (%)	Discussing fertility and referral (%) <sub>b</sub>	Two most mentioned barriers (%)
Kcimm-Malpass <i>et al.</i> [23]	2014	United States	NCI-designated cancer centers	Nurses	94	52	55.3%	a, b	dsds uncertainty and concern, alongside higher levels of depression (not specific to fertility: CES-D) and cancer or fertility-related traumas	Rarely/never discussing FP by 73.1%. Referral N.A.	Lack of available information, patient cannot afford FP
Chung <i>et al.</i> [13]	2016	China (Hong Kong)	Clinicians working in Hong Kong	Oncology; hematology, gynecology; pediatricians, surgery physicians	467	167	36.5%	a, b	45.6% reported familiarity with FP.	Percentage of discussing N.A. 68.3% never referred for FP.	No time before treatment 60.6%, risk of cancer recurrence 53.8%
Takeuchi <i>et al.</i> [47]	Unknown	Japan	Nationwide	Physicians involved with cancer patients	412	180	43.7%	a, b	N.A.	Discussing fertility 42.7% sometimes, always. Referral N.A.	Insufficient knowledge
Shah <i>et al.</i> [46]	Unknown	United States	Members Society of Gynecologic Oncology	Gynecologic oncologists	1087	152	14%	a	N.A.	Assess fertility status 68% always. Referral easy according 64.9%.	Predictors: number of young women, cancer stage.
Rosenberg <i>et al.</i> [40]	2015	United States	Oncologists involved in endocrine studies.	Medical oncologists caring for patients with breast cancer	301	93	31%	a	N.A.	Discussing fertility 98%, referral 97%	Cost/insurance 47%; patient does not want to discuss FP 27%.

**Supplement 1.** Overview of quantitative surveys among care providers regarding knowledge, practice, referral and barriers about the discussing of fertility and FP with cancer patients of childbearing age; 1) conducted/published in the past 10 years, 2) excluding qualitative studies and studies concerning pediatric care providers. (continued)

Study	Year of survey	Country	Study population	Type of care providers	Eligible participants	Final participants	Completion rate (%) <sup>a</sup>	Female (a) and male (b) patients	Knowledge of FP (%)	Discussing fertility and referral (%) <sup>b</sup>	Two most mentioned barriers (%)
Micaux <i>et al.</i> [34]	2015	Sweden	National	Physicians in oncology/hematology	821	329	55%	a, b	High knowledge male risk fertility 59%, female risk fertility/early menopause 65%	Discussing fertility: 74% female, 70% male; discussing FP 57% female, 63% male	Poor prognosis 78%, patient anxious or overwhelmed by having cancer 54%
Krouwel <i>et al.</i> [26]	2012	The Netherlands	Members Dutch Oncology Nursing Society	Oncology nurses	N.A.	421	N.A.	a, b	Sufficient knowledge of FP options: 31.1%.	Discussion of FP in more than half of the cases 42.6%	Lack of knowledge 25.2%, poor prognosis 16.4%
Ghazeei <i>et al.</i> [18]	2012-2013	Lebanon	Lebanese Society Medical Oncology, practitioners two medical centers	Oncologists, clinical practitioners (i.e. students, doctors and nurses)	81 oncologists, all practitioners	53 oncologists, 88 practitioners	65.4% for oncologists	a, b	92.3% of oncologists estimated sperm cryopreservation should be done.	73.1% of oncologists routinely discussed, 39.6% regularly refers to fertility specialist	N.A.
Buske <i>et al.</i> [11]	2011-2012	Germany	Oncologists	Oncologists	Unknown.	120	Unknown.	a, b	49.6% knowledge sperm preservation, 37.3% well informed about FP measures.	Discussing possible fertility impairment by 65.8%, FP by 65.3%. Referral by 96.6%	Poor prognosis 62.7%, over 35 years 47%
Biglia <i>et al.</i> [8]	Not reported.	Italy	Breast surgeons, oncologists	Representatives of all Italians regions	Unknown.	181	Unknown.	a	N.A.	91% discusses fertility, 60% referral	N.A.
Louwe <i>et al.</i> [31]	Not reported.	The Netherlands	2 comprehensive cancer centers	Gynecologists, oncologists, surgeons, radiotherapists, hematologists	206	96	46.6%	a	N.A.	62% took action to protect the ovarian function	Poor prognosis or need for immediate therapy 62%, costs

**Supplement 1.** Overview of quantitative surveys among care providers regarding knowledge, practice, referral and barriers about the discussing of fertility and FP with cancer patients of childbearing age; 1) conducted/published in the past 10 years, 2) excluding qualitative studies and studies concerning pediatric care providers. (*continued*)

Study	Year of survey	Country	Study population	Type of care providers	Eligible participants	Final participants	Completion rate (%) <sup>a</sup>	Female (a) and male (b) patients	Knowledge of FP (%)	Discussing fertility and referral (%) <sup>b</sup>	Two most mentioned barriers (%)
Adams <i>et al.</i> [1]	Not reported.	United Kingdom	Members doctors.net. of GMC registered doctors.	Medical and clinical oncologists	1488	100	N.A.	a, b	Sperm preservation 64% sufficient; ovarian preservation 82% insufficient.	Providing informed consent 97%, 45% routinely referral fertility specialist	Perception FP poor success rates 81%, lack of knowledge 63%
Duffy <i>et al.</i> [16]	Not reported.	United States of America	National; sample American Medical Association.	Oncologists, hematologists, radiation oncologists, gynecologists	1088	344	31.6%	a, b	±50% moderate/high knowledge confidence in fertility/ FP options.	Not reported.	Not reported.
King <i>et al.</i> [24]	Not reported.	United Kingdom	Cancer institutes, networks, associations.	Nurses, nurse specialists, oncology/surgery residents, surgeons, oncologists.	N.A.	306	N.A.	a	Knowledge local preservation options variable.	Always discussed 48%, most of the times discussed 34%.	Age (77%), disease status (37.9%)
Arafa <i>et al.</i> [3]	Not reported.	Saudi Arabia	3 regions; Eastern, Jeddah and Riyadh.	Medical, radiation and surgical oncologists.	180	103	57.2%	a, b	Familiarity with ICSI 49.5%.	Routinely discussing cryopreservation 41.7% Referral 19.5%.	Type of cancer (92%), age of patient (87%)

N.A.: Not available

<sup>a</sup> Eligible participants/final participants (%)

<sup>b</sup> Discussing of FP depending on how questions have been phrased.

## Analysis

Data analysis was performed using SPSS (Release 22; SPSS Inc., USA). Frequency distribution was used to calculate demographic information. Respondents were recoded regarding age (set at median age 47: 46 years or under vs. over 46), experience (0-10 years vs. 11 years or more), knowledge (none to some vs. sufficient to a lot) and residents vs. qualified specialists. Observed differences between demographic information and specific answers were identified using the Pearson's chi-square test, linear-by-linear association, paired T-test and independent sample T-test. *P*-values < 0.05 were considered statistically significant.

## Ethics

In The Netherlands, studies that do not involve patients or interventions are not subject to approval from an ethical board. The ethical board was consulted for a comparable previous study, as the study did not concern 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 official ethical approval was needed.

## RESULTS

### Demographics

Of the 433 invited participants 209 responses were received, resulting in a response-rate of 48.3%. Of the 209 responses, 26 oncologists reported to be retired, 6 physicians were not medical oncologists and 9 were returned to sender. Forty-eight oncologists reported they were not willing to participate due to a lack of time (*n*=35), a lack of interest (*n*=2), a lack of experience (*n*=2), the length of the instrument (*n*=4) or other reasons (*n*=5). Out of 392 eligible participants, 120 oncologists completed the questionnaire (30.6%). Majority of the respondents reported breast cancer (73.3%) and colorectal cancer (65.8%) as area of expertise (multiple areas of expertise possible). For extensive information on the respondents characteristics see Table 1.

**Table 1.** Demographic characteristics

Demographic characteristics (n=120)	n (%)
<b>Age (years)</b>	
Mean 45.8	119 (99.2)
Median 47 (range 30-64)	
<b>Gender</b>	
Male	56 (46.7)
Female	63 (52.5)
Unknown	1 (0.8)

**Table 1.** Demographic characteristics (*continued*)

Demographic characteristics (n=120)	n (%)
<b>Oncology experience (years)</b>	
1–2	19 (15.8)
3–5	27 (22.5)
6–10	13 (10.8)
11–15	19 (15.8)
>15	40 (33.3)
Unknown	2 (1.7)
<b>Function</b>	
Oncologist	74 (61.7)
Oncologist and haematologist	15 (12.5)
Haematologist	12 (10)
Resident medical oncology	19 (15.8)
<b>Hospital type</b>	
University hospital	40 (33.3)
Top clinical teaching hospital	27 (22.5)
District general hospital	47 (39.2)
Categorical cancer hospital	3 (2.5)
University hospital and district general hospital	2 (1.7)
Unknown	1 (0.8)
<b>Areas of interest<sup>a</sup></b>	
Breast cancer	88 (73.3)
Colorectal cancer	79 (65.8)
Palliative medicine	57 (47.5)
Urological cancer	55 (45.8)
Gynaecological cancer	53 (44.2)
Haematology	37 (30.8)
Lymphoma	32 (26.7)
Neuroendocrine cancer	15 (12.5)
Head and neck cancer	14 (11.7)
Melanoma	9 (7.5)
Sarcomas	8 (6.7)
Lung cancer	3 (2.5)
Experimental research (phase I-II)	3 (2.5)
Gastro-intestinal	2 (1.7)
Hepatic and biliary tract cancer	1 (0.8)

a) Multiple areas of interest possible.

## Practice

When it comes to discussing the impact of cancer treatment to fertility, almost seventy percent of respondents (n=82, 68.3%) stated to discuss fertility often or always, 20% (n=24) declared to discuss it in more than half of the cases, 5.8% (n=7) in half of the cases, 3.3% (n=4) in less than half of the cases and 2.5% (n=3) hardly never/never. Among oncologists working in a district general hospital, it was less usual to discuss fertility. In district general hospitals 84.1% discussed fertility in more than half of the cases vs. 90.3% in all others hospitals ( $p=0.033$ , linear-by-linear). No significant differences were observed regarding gender, all different specialties, residents vs. oncologists, age through 46 years or older, experience through 10 years or more, level of knowledge and availability of a department protocol.

When cancer treatment has the prospect to cure, almost all respondents (n=114, 98.3%) discuss fertility. Yet, if cancer treatment has no prospect of cure, only half of the respondents (n=61, 52.6%) discuss fertility. When treatment is at palliative stage, a quarter of the respondents stated to discuss fertility (23.3%, n=27).

Fertility is discussed with women until the age of 44 on average (range 35-100 year, SD 8.2, n=114) and on average with men until the age of 53 (range 37-100, SD 10.6, n=107).

Topics that were reported to be discussed with women, are a desire to start a family (n=120, 100%), menopausal symptoms (n=105, 87.5%), fear for premature termination of pregnancy (n=15, 12.5%), fear for congenital abnormalities (n=51, 42.5%) and heredity (n=79, 65.8%). With men, frequently discussed topics were a desire to start a family (n=117, 97.5%), erectile dysfunction (n=60, 50%), ability to ejaculate (n=24, 20%), fear for congenital abnormalities (n=39, 32.5%) and heredity (n=63, 52.5%).

## Knowledge

To the question: 'How much knowledge do you possess regarding FP for cancer patients?', 47.5% of the respondents (n=57) answered sufficient knowledge, 41.7% (n=50) had some knowledge, 7.5% (n=9) said they did not have much knowledge and 3.3% (n=4) reported they possessed a lot of knowledge. Oncologists estimated their knowledge significantly higher in comparison to residents (linear-by-linear association  $p=0.004$ ).

Three-quarters of the oncologists (n=86, 75.4%) would like to improve their knowledge towards fertility issues and management of fertility issues. Residents significantly more often wish to improve their knowledge ( $p=0.041$ ). Experience however, is not of significant influence to the wish for more knowledge ( $p=0.081$ ). Almost three-quarters (n=84, 74.3%) of the respondents believe there is too little attention for fertility issues and management of fertility issues during residency. Respondents estimated that initial cryopreservation of semen would cost 693,15 euro (range 30-15000 euro; SD 1801; n=75) with an annual cost for cryopreservation of 103,07 euro (range 0-500 euro; SD 124.8; n=75).



## Local practice

Approximately forty percent (n=45, 38.5%) of the respondents reported a protocol or a standard at their current workplace stating the routine discussing of fertility, 41.9% (n=49) did not have such a protocol and 19.7% (n=23) was not aware of such a protocol. During multidisciplinary oncology meetings, according to 37.1% (n=43) fertility is regularly discussed. Seventy-three oncologists (62.9%) reported fertility is not routinely discussed in multidisciplinary meetings. Half of the oncologists reported there is sufficient patient information available in their department regarding fertility (n=56, 48.3%), a quarter (25%, n=29) reported there is not sufficient information and the remaining quarter (26.7%, n=31) did not know whether patient information is available. Seventy percent often or always registered fertility consultation in the patient's file (n=82), 12 percent (n=14) does so in more than half of the cases and 21 oncologists (18%) reported to register in half of the cases or less. Eighty-four percent (n=101) never/hardly never prescribed a gonadotropin-releasing hormone agonist (GnRH-A) before starting chemotherapy, for protection of the ovaria. Twelve oncologists (10%) did so in less than half of the cases, 2.5% (n=3) in half of the cases and 3.3% (n=4) did so in more than half of the cases or almost always.

## Responsibility

According to 36.4% (n=43), responsibility for the discussion of fertility was assigned to their department, 53 oncologists (44.9%) stated there were no agreements regarding responsibility and 18.6% (n=22) did not know if there were agreements. Majority of the participants 93.2% (n=110, question answered by n=118) was convinced that it is the responsibility of the oncologist to discuss fertility with patients of reproductive age, 5.8% (n=7) disagreed to this responsibility. One oncologist did not know whether it is within the treatment responsibility to discuss fertility. In addition, 78% (n=92) believed that there is also a responsibility for the oncology nurse, 17% (n=20) did not believe that it is the oncology nurses' responsibility to address fertility and 5.1% (n=6) did not know if it should be oncology nurses' responsibility.

## Barriers

The respondents were given a list of 30 possible barriers for discussing fertility, in order for them to indicate to which extent they agreed. The three barriers most agreed upon by the respondents were: 'Prognosis is poor' (53%), 'Unlikely patient will survive treatment' (43.1%) and 'High chance on fertility recovery after treatment' (28.7%). The three the barriers most disagreed upon by respondents were: 'Patient cannot afford treatment' (91.3%), 'Patient is single' (90.6%) and 'No contact information available of fertility specialist' (88.8%). A complete overview of barriers can be found in Table 2.

**Table 2.** Barriers towards discussing fertility

I would tend not to discuss fertility with a patient because:	Agree	Neither agree nor disagree	Disagree
	n (%)	n (%)	n (%)
Patient cannot afford treatment	1 (0.9)	9 (7.8)	105 (91.3)
Patient is single	2 (1.7)	9 (7.7)	106 (90.6)
No contact information available of fertility specialist	2 (1.7)	11 (9.5)	103 (88.8)
Patient is a teenager	3 (2.8)	4 (3.7)	101 (93.5)
This may raise fear and discomfort	3 (2.5)	20 (17)	95 (80.5)
Semen cryopreservation is not adolescent friendly	3 (2.7)	20 (17.7)	90 (79.6)
Uncomfortable to discuss fertility	4 (3.5)	23 (20.4)	86 (76.2)
Patient already has a child/children	5 (4.3)	22 (18.8)	90 (76.9)
Semen cryopreservation is expensive for patient	5 (4.5)	28 (25.2)	78 (70.3)
Hereditary tumor (risk of passing to child)	7 (6)	17 (14.5)	93 (79.5)
Pregnancy during or after chemotherapy may induce malformation of child	8 (6.9)	26 (22.4)	82 (70.7)
I do not possess enough knowledge regarding fertility preservation options	8 (6.8)	27 (23.1)	82 (70.1)
Patient is homosexual	10 (9)	19 (17.1)	82 (73.9)
Fear of possible malignant transformation of ovarian tissue	11 (9.7)	18 (15.9)	84 (74.3)
Fertility treatment may influence success of cancer treatment	12 (10.3)	27 (23)	79 (66.7)
Treatment delay	12 (10.3)	27 (23.1)	78 (66.7)
Patient does not bring up the subject	13 (11)	25 (21.2)	80 (67.8)
Possibility of reintroducing cancer or metastasis by ovarian tissue cryopreservation	13 (11.4)	26 (22.8)	75 (65.8)
Culture or religion of patient does not support assisted fertility	13 (11.5)	32 (28.3)	68 (60.2)
Curation has priority	19 (16.2)	33 (28.2)	65 (55.6)
Difficult to predict risk for deteriorated fertility	19 (16.4)	33 (28.4)	64 (55.2)
Ovarian tissue cryopreservation is experimental	20 (17)	36 (30.5)	62 (52.5)
Patient is treated before with chemo and/or radiotherapy	23 (19.8)	30 (25.9)	63 (54.3)
Lack of time during consult	25 (21.4)	22 (18.8)	70 (59.8)
Patient is HIV positive	28 (25.7)	26 (23.9)	55 (50.4)
Hormonal treatment may increase risk of recurrence	28 (25)	31 (27.7)	53 (47.3)
Patient is not able to ejaculate, therefore cryopreservation is not possible	31 (27.4)	22 (19.5)	60 (53.1)
High chance on rapid recovery of reproductive function after treatment	33 (28.7)	31 (27)	51 (44.3)
Unlikely patient will survive treatment	50 (43.1)	25 (21.6)	41 (35.3)
Prognosis is poor	62 (53)	27 (23.1)	28 (23.9)

For ease of presentation, results in response categories 'Strongly agree' and 'agree' have been merged, as have 'strongly disagree' and 'disagree'. Total number of respondents may differ per barrier, as some respondents skipped barriers.

## Referral to fertility specialist

When asked which percentage of all patients of reproductive age has been referred to a fertility specialist, on average 44.6% of men (range 0-100%; SD 37.1), and on average 28.9% of women (range 0-100%; SD 31.4), is referred. The percentage of women being referred is significantly

lower in comparison to men ( $p < 0.001$ , paired T-test). The percentage of men being referred was more often by oncologists of 47 years and older ( $p = 0.028$ , ind. sample T test) and by residents ( $p = 0.001$ , ind. sample T test). There were no significant differences in gender or hospital type of the respondents in reference to the percentage of referred patients.

## **Ethics**

The participating oncologists were asked to give their opinion upon post-mortem use of preserved material for assistant reproduction for the partner. Half of the oncologists ( $n = 56$ ) believed this is acceptable, 39 oncologists (35.5%) believed this is not acceptable and 15 oncologists (13.6%) were not aware of the existence of this possibility.

## **DISCUSSION**

### **Main findings**

Considering it is crucial that medical oncologists address the impact of cancer treatment to fertility with patients of childbearing age, this survey intended to represent current practice and knowledge among medical oncologists practicing in the Netherlands. Main findings of our study demonstrate an accountable attitude with regards to fertility issues among responding oncologists, yet about two-third of the participants stated to often or always discuss the impact to fertility. Practice behavior is mainly influenced by patients' prognosis, type of hospital and fertility recovery chances. On average, 44.6% of reproductive men and 28.9% of reproductive women are referred to a fertility specialist. Half of our respondents said to possess sufficient knowledge concerning FP. Three-quarter of the oncologists believed too little training is paid to the subject during residency and expressed a wish for additional education on fertility issues and preservation options.

### **Comparison to literature and interpretation of findings**

In the past decade, several international surveys have been performed amongst oncology care providers regarding the provision of FP (Supplement 1). Response-rates of previous surveys differ from 14 to 78.6 percent (mean 47.3%). Much of what is known about fertility and cancer is the result of studies conducted in the US, the UK and other countries. Two studies have been performed in the Netherlands, reflecting on the practice of physicians from several different cancer specialties, not solely medical oncologists. Our findings indicate that responsibility for fertility concerns is acknowledged by oncologists, however in practice the discussing of fertility concerns may vary. Other surveys among oncologists across the world show greatly varying results, with discussing percentages ranging from 13.6 to 98 percent and referral percentages from 15 to 97 percent (Supplement 1). Although the counselling percentages vary in countries

and regions, it is clear that we are facing a generic concern probably applicable to all cancer care institutes in a greater or lesser extent.

In comparison to previous surveys worldwide, the surveyed oncologists score average on discussing fertility concerns in practice. As for referral to a fertility specialist, scores of the Dutch oncologists are slightly lower than average. However, most of the reviewed surveys were conducted in single centers, selected populations (e.g. among oncologists who had previously enrolled women on premenopausal studies) or demarcated areas, and often only investigated FP regarding female cancer or breast cancer patients as seen in Supplement 1. Therefore the questioned populations may be biased, as local practices may differ significantly. Differences in several types of practices are empowered by our finding that oncologists employed in a district general hospital were less likely to discuss fertility issues. This proven variety in practice between district general hospitals and top clinical- and university hospitals may be explained by limited access to fertility departments which are usually located in university or top clinical teaching hospitals. This phenomenon was previously observed by Hariton *et al.*, showing the association between the establishment of a oncofertility clinic and increased consultations for FP [17]. In addition, a recent Dutch survey showed the relevance of available reproductive specialists with specific expertise with regards to women with cancer, as a lack of available specialists was reported a major barrier against discussing fertility issues with patients [25]. Furthermore, Louwe *et al.* revealed a positive correlation between the number of FP options available and the number of information sources available in regards to confidence in the physicians' knowledge [25]. Negative correlation was shown between the frequency of discussion fertility issues and a lack of reproductive specialists in the geographic region, which is very similar to our results.

Barriers most mentioned by our respondents, were a poor prognosis and unlikelihood the patient will survive the treatment. In comparison to literature, these are often mentioned barriers towards discussing fertility issues by clinicians working in oncology departments. By way of comparison, in a Swedish survey the barrier 'poor prognosis' was mentioned by 78% [28], in a German survey by 62.7% [8], in a Dutch pilot survey by 62% [26], in a Canadian survey by 66.4% [39], in a UK survey by 78.6% [15] and in an American survey by 30% [14]. Besides medical reasons, one out of five oncologists stated lack of time during the consult as a barrier towards discussing fertility.

In addition we asked the clinicians to estimate costs of semen cryopreservation. Estimations of the costs of semen cryopreservation were variable, on average the estimated costs were fairly overestimated. Specifying, costs for initial cryopreservation were estimated €693,15, actual costs are €119,82, with additional costs per sample of €62,81 (reimbursements 2018). Annual costs for cryopreservation were estimated €103,07, actual annual costs are €60,12 (reimbursements 2018). As the costs are fairly overestimated (specifically the initial costs), patients may be informed incorrectly by their clinicians. In some cases, this may result in the decision to withhold from cryopreservation, an undesirable consequence.

Clearly, there is a reported lack of training for fertility issues and their management during residency. Consequently, a wish for additional education is expressed by the majority of the respondents, implying a major role for the development of training courses and implementation of the subject fertility issues during residency. By these means, early referral by oncologists before initiation of chemotherapy and radiotherapy will be enabled, as this is a key factor for success in (female) FP [35].

## **Strengths and limitations**

The completion rate of 30.6% is lower than the average response rate of physicians surveys [10], also on the lower limits in comparison to physicians surveys performed in the Netherlands with response rates running from 28-55% [21, 20, 12]. The completion rate may be explained by the length of the questionnaire, the content of the questionnaire (assessing treatment side-effect knowledge, which may be embarrassing if unfamiliar with this knowledge) as well as the sensitivity of the topics sexuality and fertility. Yet, a non-response bias may have occurred. Oncologists with affinity for the subject may have been more inclined to answer than oncologists who are less committed to fertility concerns. Demographic characteristics of non-responders have not been made available, consequently non-response calculations could not be made. A non-validated questionnaire has been used as a validated instrument was not available. Nevertheless, a pilot study has been conducted to check for validity and reliability. Subdivision by area of specialization resulted in small numbers of medical oncologists in each specialization group. Accordingly, it was not possible to do sub analyses for every separate area of specialization.

## **Clinical implications**

Awareness and sufficient knowledge among medical oncologists regarding possible toxic effects to endocrine and reproductive health is of critical importance for young men and women with cancer. Due to a lack of knowledge, referral possibilities and counselling barriers the ability to start or complete a family after treatment may not be extensively discussed. Subsequently many men and women of reproductive age with cancer could be missing the opportunity to investigate their FP options. We recommend expansion of education of fertility treatment risks and preservation options starting in medical school, continued during residency training and updates when practicing as a medical oncologist. A culture of shared decision making should be pursued, through the development of clear fertility referral pathways including psychosocial support to improve care for men and women of childbearing age facing a cancer treatment.

## **CONCLUSION**

In conclusion, the results suggest that medical oncologists take responsible attitudes towards fertility preservation in oncology practice. Self-reported knowledge regarding fertility preserva-

tion is strongly varying and the majority expressed a wish for additional education. Practice attitudes remain under influence of factors like poor prognosis, a lack of knowledge, treatment-delay and local availability of fertility specialists. Efforts to develop educational training on treatment fertility risks, communication skills and acquaintance with fertility preservation options are highly recommended. Improvement of awareness regarding fertility preservation and in addition availability of fertility specialists in district general hospitals may increase referral of young cancer patients for fertility preservation. Timely referral to discuss preserving options for endocrine and reproductive health is crucial, before irreversible damage to the gonads is done.

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# Chapter 11

## *Identifying the Need to Discuss Infertility Concerns Affecting Testicular Cancer Patients: An Evaluation (INDICATE Study)*

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## INTRODUCTION

Testicular cancer (TC) is the most common type of cancer affecting men between 15 and 44, particularly in white Caucasian populations [1]. Over the past decades, in industrialised countries, and especially in Northern and Western Europe, TC incidence has increased and continues to rise [2]. In the Netherlands, the incidence has doubled in the past two decades, with over 800 men diagnosed every year [3]. At diagnosis, patients with TC are staged according to the presence and site of metastatic lesions and the serum levels of tumour markers. Most patients diagnosed with TC are primarily treated with orchiectomy, and subsequent therapy depends on the tumour histology, stage and prognosis group [4]. Adjuvant treatment may involve surveillance, chemotherapy, nerve-sparing retroperitoneal lymph-node dissection (RPLND) or radiotherapy.

Cure rates for non-metastatic TC are excellent and even for metastatic TC patients are the chances of cure and long-term survival high because of greatly effective chemo- and radiotherapy [5]. High five-year-survival rates make quality of life important to consider in the treatment of TC, as many TC patients survive for decades after being diagnosed [5,6]. TC, together with poor semen quality, hypospadias, and undescended testis, is part of the testicular dysgenesis syndrome [7]. Gonadal dysfunction with subnormal testosterone levels in TC survivors is common after treatment, which has a major impact on quality of life [8,9]. Moreover, treatment of TC can either temporarily or permanently impair fertility [10]. Chemotherapy and radiotherapy are likely to impair spermatogenesis and RPLND may impact ejaculatory function [11]. Compared to the normal population, fertility decreased by 30% in TC patients after treatments, radiotherapy has the most deleterious effects [10]. However, sperm abnormalities and Leydig cell dysfunction are often already present in TC patients prior to orchiectomy due to testicular dysgenesis syndrome: 24% has azoospermia and almost 50% has oligozoospermia before surgery [12,13,14]. After orchiectomy, concentration and total sperm counts deteriorate further, especially in non-seminoma patients [13].

Taking into account pre-existing sperm abnormalities in TC patients and the chances of deteriorating fertility after treatment, fertility is a critical subject for health care providers to discuss with patients prior to commencing treatment [15,16]. Besides discussing the possibility of impaired fertility, TC patients should be offered cryopreservation prior to the start of treatment and sperm cryopreservation should be encouraged to maintain the ability to conceive a child in later life [4]. In the Netherlands, it is common practice that, within 48–72 h after diagnose, orchiectomy should follow. Health care providers are advised to discuss the risk of impaired fertility and propose cryopreservation as soon as possible after diagnose [17]. Within a short period of time after diagnosis, TC patients are confronted with not only the impact of having cancer, but also uncertainty of the possibility to have children. Sperm cryopreservation is a generally accepted method to preserve fertility in men [18]. Sperm used for cryopreservation is obtained by ejaculation or via alternative approaches in case of impairment in sperm

retrieval, like percutaneous epididymal sperm aspiration (PESA) and testicular sperm extraction (TESE). Additionally, sperm cryopreservation has proven to be the most cost-effective strategy for fertility preservation in men with TC prior to undergoing chemotherapy or radiotherapy [19]. In the Netherlands, sufficient sperm banks exist to offer cryopreservation within 48 h after diagnosis, prior to orchiectomy [20]. In one out of six patients, sperm cryopreservation could be unsuccessful due to severe spermatogenesis impairment [20]. This is an important argument for performing sperm cryopreservation prior to radical orchiectomy. In these patients, testicular sperm extraction (TESE) can be performed during radical orchiectomy [13,20].

According to literature, 17% of TC patients were not offered cryopreservation [21] and barriers exist for health care providers to discuss the fertility topic [22,23]. Furthermore, a lack of information provision regarding sperm cryopreservation is identified as the biggest barrier for young male cancer patients for actually performing sperm preservation [24]. Little is known about the long-term fertility and paternity rates, and the use of preserved semen and spontaneous versus assisted paternity rates of TC survivors.

In order to evaluate fertility related issues according to men who have faced TC, a survey has been performed among TC survivors in the Netherlands. The survey included questions regarding patients' experiences of the discussion of fertility concerns and sperm preservation, the procedure of sperm cryopreservation, the number of children and the use of preserved samples, satisfaction levels regarding information provision and reproductive concerns.

## MATERIALS AND METHODS

### Study Design

A cross-sectional study has been performed among TC patients at the time of January-June 2016 ( $n = 611$ ). All TC patients diagnosed or treated at Leiden University Medical Center between 1995 and 2015 received an invitation to participate. Leiden University Medical Center is a tertiary referral centre for post radical orchiectomy treatment. By these means, orchiectomy and fertility counselling could have been performed in several peripheral hospitals from the region, after which patients have been referred to the Leiden University Medical Center for treatment and/or follow up. Men that were deceased or moved abroad have not been approached ( $n = 29$ ), resulting in 582 eligible patients. Patients received a letter by mail explaining the study objectives and a consent form with a post-paid return envelope. Consent forms were coded in order to link respondents to an anonymized file including patients' treatment history. Reminders were sent to non-responders after 6 weeks. When consent was provided, patients received the questionnaire accompanied by a post-paid return envelope.

## Inclusion Criteria

Patients who are or have been under treatment of the outpatient clinic of the Urology and/or Oncology department of the LUMC with pathologically confirmed TC in their medical history. Inclusion criteria: ability to understand and fill in the questionnaire in Dutch, willingness and informed consent to participate. We excluded TC patients under 18 years old at the time of diagnosis, and deceased or patients who moved abroad. Furthermore, we excluded patients sterilized previous to diagnosis. Upper age criterium was set after checking all Dutch fertility clinics and guidelines. We found that some clinics have a maximum age of 60 years; others do not have a maximum. As we had one respondent of 79 years old explicitly stating fertility questions were not applicable, we decided to exclude respondents that were 70 years old or older.

## Materials; Questionnaire

The questionnaire was designed by the researchers, based on the study aims and a review of the literature in the area. The Dutch validated Reproductive Concern Scale has been implemented, minimally adjusted to a male perspective [31,32]. A multidisciplinary expert panel, having experience developing surveys and having experience regarding fertility and oncology, checked the questionnaire for comprehensiveness and quality. A patient panel of two members of the Dutch Testicular Cancer Society piloted the questionnaire afterwards.

The questionnaire focussed on patients' experience discussing fertility, cryopreservation and the quality of the information provided. Additionally, the advice given by health care providers, patients' preference regarding discussing fertility and the experience of cryopreservation were taken into account. Lastly, the provision of information and satisfaction about testicular implants were assessed, and these results have been processed separately [33].

## Data Analysis

Data of the questionnaires were transferred into digital files. Additional data were obtained from the oncology registration (anonymized), including age, type and staging of TC and treatment types. Demographic data of non-respondents have been compared to respondents. Data analysis was performed using SPSS (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp., USA). Means of numerical demographic values and the answers to the questions have been analysed with frequency distribution. Bivariate associations between demographic information and the categorical data were calculated using the Pearson chi-square procedure and linear-by-linear association. Associations between numerical data and demographics of the respondents were analysed with the independent sample *t*-tests. Two-sided *p* values < 0.05 are considered statistically significant.



# Ethics

Ethical approval was obtained at the local medical ethical committee, as it concerns a survey with sensitive questions. Approval was provided on 7 October 2015. A letter explaining the study and an informed consent form was provided before introducing the questionnaire.

# RESULTS

From 582 invited participants, 262 responses were received (response rate 45%), of which 45 patients refused to participate. The reasons were: ‘no time’ (6), ‘no interest’ (18), ‘the diagnosis was too long ago’ (3), ‘treatment took place in another hospital’ (3), ‘bilateral orchiectomy so fertility was not an issue at the time’ (1), ‘due to my age not applicable’ (4), ‘too many requests for participation in research’ (2), ‘prefer digital questionnaire’ (1), ‘did not receive treatment’ (1) and some reported no reason (6). Excluded were patients ‘not understanding the questionnaire in Dutch’ (6), ‘mentally not capable’ (2), ‘questionnaire not relevant as patient was already sterilized prior to diagnosis’ (2). Six respondents were excluded due to their age (>70 years old at time of diagnosis). These exclusions resulted in 566 eligible candidates.

A total of 201 questionnaires among the 566 eligible candidates (35.5%) have been returned. The responders and non-responders did not differ in mean age at the time of the questionnaire (44.2 years vs. 43 years) and mean age at diagnosis (33.7 years vs. 34 years). A difference was found in the mean follow-up time. The follow-up was 10.6 years for responders and 9.2 years for non-responders ( $p = 0.004$ , ind. sample T test).

Demographic characteristics are shown in Table 1. The mean time since diagnosis was 11 years and the mean age at diagnosis was 34 years. A majority of 81.1% was married or living together at the time of the survey and 88.6% was born in the Netherlands.

**Table 1.** Demographic characteristics

Demographic characteristics	n (%)
Total eligible patients	566 (100)
Total participation rate	201 (35.5)
Mean age: 44.2 years (range 23-74)	201 (100)
Mean age at time of diagnosis 33.7 years (range 20-68)	201 (100)
Mean follow up time to questionnaire 10.6 years (range 2-21)	201 (100)
<b>Histology</b>	
Seminoma	101 (50.2)
Non-seminoma	96 (47.8)
Neuro-endocrine	1 (0.5)
Leydig cell tumour (malign)	3 (1.5)
<b>Histology contralateral tumour</b>	<b>7 (3.4)</b>
Seminoma	2 (28.6)
Non-seminoma	4 (57.2)

**Table 1.** Demographic characteristics (*continued*)

<b>Demographic characteristics</b>	<b>n (%)</b>
CIS	1 (14.3)
<b>Tumor stadium</b>	
Stage I	103 (51.2)
Stage II	29 (14.4)
Stage III	2 (1)
Stage IV	7 (3.5)
Unknown	60 (29.9)
<b>Primary treatment</b>	
Primary orchiectomy <sup>a</sup>	200 (99.5)
Chemotherapy	1 (0.5)
Orchiectomy for contralateral tumour	7 (3.5)
<b>Secondary</b>	
Surveillance	48 (23.9)
<i>Additional therapy</i>	
Chemotherapy	96 (47.8)
+ RPLND	21 (10.4)
+ RT	3 (1.5)
+ RPLND & RT	1 (0.5)
+ Metastasectomy	3 (1.5)
+ RT + Metastasectomy	1 (0.5)
Metastasectomy <sup>a</sup>	1 (0.5)
Radiotherapy	27 (13.4)
<b>Marital status</b>	
Married/registered partnership	116 (57.7)
Relationship, living together	47 (23.4)
Relationship, living apart	13 (6.5)
Single	18 (9.0)
Divorced	4 (2)
Widow	1 (0.5)
Unknown	10 (5)
<b>Educational level</b>	
Secondary school	36 (17.9)
Secondary vocational education	50 (24.9)
Higher professional education/University	115 (57.2)
<b>Country of birth</b>	
<b>Country of birth</b>	
Netherlands	178 (88.6)
Other ( <i>USA 1, Colombia 2, Germany 3, France 1, Indonesia 2, Iran 1, unknown 13</i> )	23 (11.4)

a) a single patient did not primarily receive an orchiectomy as there was a burned out tumour; presenting with metastasis.

## Information Provision Regarding Fertility Preservation

The majority of the respondents (87.6%,  $n = 176$ ) stated to be notified about the possibility of fertility problems as a result of their treatment. Nineteen patients (9.5%,  $n = 19$ ) stated that, as far as they remember, they have not been informed about the possibility of diminished fertility, six respondents could not remember (3%). Patients who had not been informed about possible fertility issues were mostly stage I ( $n = 15$ ), stage II ( $n = 1$ ) and from three patients the stage was unknown. The possibility of sperm cryopreservation was mentioned according to 77.1% of the respondents ( $n = 155$ ); it was not mentioned according to 29 respondents (14.4%).

More than half of respondents were informed about the possibility of fertility problems by their urologist (57.7%,  $n = 116$ ), of which 74.1% of the time in advance of the orchiectomy and 12.9% in advance of chemotherapy. Information provision regarding fertility threat by other health care providers and timing of information provision is displayed in Table 2.

**Table 2.** Information provision regarding the possible reduced fertility.

Health care provider	Percentage of discussing fertility by specific provider	Timing	In advance of orchiectomy	In advance of chemotherapy	In advance of radiation
	n (%)		n (%)	n (%)	n (%)
Urologist	116 (57.7)		86 (75.4)	15 (13.2)	5 (4.4)
Medical oncologist	93 (46.3)		10 (10.9)	64 (69.6)	5 (5.4)
Radiation oncologist	2 (1)		-	-	2 (100)
General practitioner	4 (2)		4 (100)	-	-
Oncology nurse	15 (7.5)		1 (6.7)	12 (80)	-
Fertility specialist	21 (10.4)		2 (10)	15 (75)	-

Conversations regarding fertility preservation were initiated by the patient itself ( $n = 10$ , 9.5%), a doctor ( $n = 144$ , 71.6%), a nurse ( $n = 10$ , 5%), their partner ( $n = 2$ , 1%), or it had not been discussed ( $n = 4$ , 2%). A minority stated ‘it was not at risk according to my doctor’ ( $n = 2$ , 1%), one respondent said ‘I only got a referral to a fertility specialist but no explanation’ (0.5%) and one participant could not remember (0.5%). A quarter of all respondents received written information materials ( $n = 48$ , 23.9%) regarding fertility issues, 62.7% did not receive written information ( $n = 126$ ). The majority prescribed the provided information as extensive ( $n = 33$ , 68.8%), 22.9% would have liked more extensive information ( $n = 11$ ), two patients stated information was incomplete (4.2%). Patients found additional information on the internet ( $n = 17$ ), through the Dutch Testicular Cancer Society ( $n = 15$ ), the ‘KWF’ foundation ( $n = 3$ ), Google ( $n = 10$ ), and family and friends ( $n = 4$ ).

## Patient Preferred Information Provision

Participants were asked to state their preference regarding the most suitable health care provider for information provision on fertility preservation. Preferences are displayed in Table 3.

**Table 3.** Patient preferred a health care provider for counselling on treatment related fertility problems.

Preferred health care provider	n (%)
Urologist	95 (47.3)
Oncologist	61 (30.3)
General practitioner	7 (3.5)
(Oncology) nurse	11 (5.5)
All above mentioned	3 (1.5)
Specialty not relevant; doctor that is initially telling diagnosis	8 (4)

## Treatment Related Advice Regarding Sperm Preservation

In Table 4, we display the (by participants reported) doctors' advices regarding sperm preservation in regards to their treatments.

## Patient Satisfaction Levels with Information Provision

Satisfaction levels regarding information provision about fertility were, respectively, very satisfied ( $n = 52$ , 27.7%), satisfied ( $n = 92$ , 48.9%), neutral ( $n = 33$ , 17.6%), dissatisfied ( $n = 6$ , 3.2%) and very dissatisfied ( $n = 5$ , 2.7%). Satisfaction levels regarding information provision about the possibility to perform sperm cryopreservation were, respectively, satisfied ( $n = 111$ , 81.6%), neutral ( $n = 11$ , 8.1%), and dissatisfied ( $n = 14$ , 10.3%).

Men that had not been informed about fertility risks and the possibility to perform sperm cryopreservation were significantly more dissatisfied with the information provision ( $p < 0.001$ , linear-by-linear association). Men that had not performed sperm cryopreservation reported significantly more dissatisfaction with information provision as well ( $p = 0.023$ , linear-by-linear association).

After finishing all treatments, 38 men reported that they had discussed their fertility concerns with a medical professional. Concerns were discussed with general practitioners (30.4%, satisfaction 85.7%), family/friends (75.5%, satisfaction 76.9%), fellow sufferers (18.6%, satisfaction 87.5%), psychologists (17.4%, satisfaction 75%) and the urologist (52%, satisfaction 56%). Twenty-nine men stated that, in retrospect, they would have wanted counselling regarding fertility concerns (14.4%).

## Sperm Cryopreservation Procedure

To the question: "was there a possibility to choose a location for sperm production", 65% answered affirmative ( $n = 54$ ). Thirty-six patients reported they had been able to produce sperm in the privacy of their home, three patients obtained sperm during clinical stay in the hospital, sixty-one patients reported an attempt in the outpatient fertility clinic. The majority (69.5%,  $n = 57$ ) was able to obtain sperm without trouble, 25.6% succeeded in collecting with some obstacles ( $n = 21$ ), one patient reported that he was unsuccessful in producing semen due to the experienced pressure from having cancer, two patients reported not to succeed due to

Table 4. Advice from physician regarding sperm preservation in relation to treatments.

Treatment	Sperm cryopreservation, significant risk reduced future fertility	Sperm cryopreservation, low risk but as a precaution	No preservation necessary	Not yet necessary, to reconsider if additional treatment is required	Varying advices were given	No advice given
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Orchiectomy and surveillance	10 (25.6)	4 (10.3)	9 (23.1)	9 (23.1)	2 (5.1)	5 (12.8)
Orchiectomy and chemotherapy	52 (61.2)	13 (15.3)	3 (3.5)	4 (4.7)	5 (5.9)	8 (20.5)
Orchiectomy and radiation	6 (31.6)	5 (26.3)	3 (15.8)	2 (10.5)	2 (10.5)	1 (5.3)
Orchiectomy, chemotherapy and radiation	0	1 (50)	0	0	0	1 (50)
Orchiectomy, chemotherapy and RPLND	15 (83.3)	1 (5.6)	0	0	1 (5.6)	1 (5.6)
Orchiectomy, chemotherapy and metastasectomy	2 (100)	0	0	0	0	0
Orchiectomy, chemotherapy, radiation and metastasectomy	0	1 (100)	0	0	0	0
Abdominal tumour; chemotherapy + metastasectomy	1 (100)	0	0	0	0	0
Total	86 (51.5)	25 (15)	15 (9)	15 (9)	10 (6)	16 (9.6)

pressure because of collection in the hospital and one patient reported not succeeding due to pain.

Participants were asked if the costs for samples and storage fees influenced their decision. Thirty-three men reported that they were not aware of additional costs, 39 men stated that the costs would not matter and seven men reported that the costs were significant, but because of the importance, not an issue. One single patient reported that the costs influenced the decision-making and decided not to perform sperm cryopreservation.

## Offspring before and after Testicular Cancer

Altogether, 83 men (41.3%) performed sperm cryopreservation. Thirteen out of 83 men (15.7%) that performed sperm cryopreservation reported that they made use of their sample(s), which is 6.5% from all 201 participating respondents. Seven out of 13 men reported the successful use of their sperm samples (53.8%). Five patients reported considering the usage of their sperm sample in the future (6%), 38 patients reported as not yet being sure about using the samples in the future (45.8%).

Off all the participants, 86 men (42.8%) already father children conceived before the diagnosis TC. After TC treatment, 63 men had children (31.3%). Twenty-nine men reported that they had one child, 27 men reported that they had two children, five men reported they had three children and one man reported four children after being treated for TC.

More information regarding children after TC in regards to the received treatments is shown in Table 5.

Finally, participants were asked if their wish to become parents had changed due to the TC diagnosis and treatments. According to the majority ( $n = 166$ , 87.4%), nothing had changed, 12 men experienced an increased wish for children (6.3%) and 12 men described a decreased wish for children (6.3%). Stage of disease was not significantly different with regards to either increased, likewise or decreased wish for children (linear-by-linear,  $p = 0.477$ ).

## Reproductive Concern Scale

In Table 6, the results from TC survivors scoring the validated 'Reproductive Concern Scale' items.

**Table 5.** Children after testicular cancer in reference to previous treatments.

Treatment	Children by natural conception	Children by use of preserved sperm sample	Children with assisted reproduction due to reduced fertility of partner	Children with assisted reproduction due to reduced fertility of patient	No children yet, attempting by natural conception at the moment	No children yet, attempting by assisted reproduction at the moment	No children yet, it was not possible	No wish to become a parent (yet)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Orchiectomy and surveillance	11 (22.9)	0 (0)	1 (2.1)	0 (0)	3 (6.3)	1 (2.1)	5 (10.4)	27 (56.3)
Orchiectomy and chemotherapy	26 (29.9)	2 (2.3)	2 (2.3)	1 (1.1)	2 (2.3)	0 (0)	3 (3.4)	51 (58.6)
Orchiectomy and radiation	7 (30.4)	1 (4.3)	0 (0)	0 (0)	1 (4.3)	0 (0)	0 (0)	14 (60.9)
Orchiectomy, chemotherapy and radiation	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	3 (100)
Orchiectomy, chemotherapy and RPLND	4 (19)	4 (19)	2 (9.5)	0 (0)	0 (0)	1 (4.8)	0 (0)	10 (47.6)
Orchiectomy, chemotherapy, RPLND and radiation	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (100)
Orchiectomy, chemotherapy and metastasectomy	1 (33.3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (66.7)
Orchiectomy, chemotherapy, radiation and metastasectomy	1 (100)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Abdominal tumour; chemotherapy + metastasectomy	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (100)
<b>Total</b>	50 (26.6)	7 (3.7)	5 (2.7)	1 (0.5)	6 (3.2)	2 (1.1)	8 (4.3)	109 (58)

**Table 6.** Results of the Reproductive Concern Scale adjusted for male.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
<i>Item on the reproductive concerns scale</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
I have concerns about my ability to have children	150 (79.4)	25 (13.2)	8 (4.2)	4 (2.1)	2 (1.1)
I am content with the number of children that I have	53 (29.1)	10 (55)	8 (4.4)	14 (7.7)	97 (53.3)
I feel less of a man because of reproductive problems	163 (84.5)	23 (11.9)	5 (2.6)	1 (0.5)	1 (0.5)
An illness/disease has affected my ability to have children	131 (70.1)	22 (11.8)	21 (11.2)	5 (2.7)	8 (4.3)
I am angry that my ability to have children has been affected	167 (87.9)	19 (10)	3 (1.6)	-	1 (0.5)
I am able to talk openly about my fertility	64 (35)	10 (5.5)	31 (16.9)	25 (13.7)	53 (29)
Others are to blame for reproductive problems	178 (94.7)	5 (2.7)	3 (1.6)	-	2 (1.1)
I am sad that my ability to have children has been affected	153 (80.5)	28 (14.7)	7 (3.7)	2 (1.1)	-
I was in control over my reproductive future	108 (57.7)	14 (7.5)	18 (9.6)	22 (11.8)	25 (13.4)
I feel guilt about my reproductive problems	178 (93.2)	11 (5.8)	2 (1)	-	-
I have mourned the loss of my ability to have children	169 (89.4)	11 (5.8)	5 (2.6)	4 (2.1)	-
I blame myself for my reproductive problems	183 (95.8)	6 (3.1)	2 (1)	-	-
I am frustrated that my ability to have children has been affected	169 (88.9)	17 (8.9)	2 (1.1)	2 (1.1)	-
I am less satisfied with my life because of reproductive problems	174 (90.6)	14 (7.3)	1 (0.5)	1 (0.5)	2 (1.0)

## DISCUSSION

This study provides us with a broad perspective regarding fertility concerns and sperm cryopreservation among men who survived TC. The results indicate that the majority of the respondents have been notified about the possibility of fertility problems as a result of their treatment (87.6%). However, the possibility of sperm cryopreservation was discussed with fewer respondents (77.1%). According to the respondents, the most suitable health care provider for counselling about fertility preservation is the urologist. Advices regarding sperm preservation in relation to treatments were strikingly variable, especially for the ‘orchietomy and surveillance’ group and the ‘orchietomy and radiation group’. In these two groups, respectively, 46.2% and 26.3% were informed that cryopreservation of sperm was not necessary (Table 4). Furthermore, varying advices were given or no advice was given at all. This is a surprising finding, realising that already before treatment, up to a quarter of TC patients are azoospermic and almost half of them have abnormal sperm counts (oligozoospermic) [13]. As for the advice regarding preservation received by patients undergoing radiation, is remarkable, as radiotherapy seems to have the most deleterious effect on fertility [10]. Written information materials regarding fertility issues were provided in less than a quarter of the respondents. This corresponds to an American survey among oncologists, where only 13.5% reported ‘always or often’ giving their patients educational materials about fertility preservation [25]. Provision of written, digital or



visual information materials could be helpful, as it is a well-known phenomenon that patients often do not remember all verbally supplied information [26]. Furthermore, provision of written information could increase patient satisfaction [27,28]. In the current survey, levels of satisfaction with care could directly be correlated to the amount of information provided regarding fertility risks. Men that did not make use of sperm cryopreservation were significantly more dissatisfied. According to two thirds of respondents, sperm collection was possible on a self-chosen location. Obtaining sperm was troublesome, but eventually possible for 25.6% of respondents; 4.8% did not succeed. Reasons for troublesome collection were high pressure due to disease, pain after surgery and uncomfortable setting in the hospital. Costs regarding sperm cryopreservation and storage fees did not influence decisions for preservation according to the majority. Different results were found in the United States, where 10% noted cost as the reason for not banking sperm [21]. Costs in the USA, however, seem to be significantly higher compared to the Netherlands, which may explain the different results. Initial sampling fees in the USA nearing \$1000 (€126.47 in the Netherlands) and yearly storage costs ranging from \$300 to \$400 (€66.29 in the Netherlands). These fees, however, are covered by every Dutch health insurance agency.

Almost one third of respondents fathered children after TC treatment. Eleven percent made use of their preserved sperm samples ( $n = 7$ ) to procreate, six men used their sample but did not succeed in conception. This means that thirteen out of 83 men (15.7%) who banked sperm made use of their sample, this is slightly more than the average usage rate of cryopreserved sperm among male cancer patients. A systematic review of 30 studies on sperm cryopreservation in male patients with cancer showed that 8% of 11.798 patients who preserved sperm made use of their sample [29]. Success in achieving parenthood among patients who used their sperm sample was 49% and our results showed a comparable conception rate (54%).

The results of the Reproductive Concern Scale showed a rate of 35% that did not feel able to talk openly about fertility. Furthermore, 57.7% stated not feeling in control of their reproductive future. Almost a third (29.1%) was not content with the number of children they fathered. Nineteen percent of the respondents reported a little bit, somewhat or quite a bit of grief due to impaired fertility, 9.3% stated being a little bit, somewhat and some even very much less satisfied in life due to impaired fertility. These results provide insight in the long-term consequences of diminished fertility among TC survivors, emphasizing the need for optimizing fertility counselling in this group.

In most of the TC patients in this study, the experience of testicular cancer did not influence the wish to have children (87%), a small amount (6%) felt it had increased their wish to be a father, and 6% felt it decreased their wish. In a survey among young male cancer patients conducted in the United States, slightly different numbers were mentioned, as 68% of their wishes was not influenced, 16% felt an increased and 16% a decreased wish to become a father [24].

## Limitations

Limitations of this survey include the use of a partially non-validated questionnaire. However, by involving a multidisciplinary expert panel and a patient panel checking for comprehensiveness and quality, we aimed to reduce any bias resulting from the use of this questionnaire. Furthermore, it is possible that a recall bias has occurred, due to the relatively long period between diagnosis, treatment and questionnaire. In addition, with a growing attention on oncofertility in the past decade, the survey may not be representative for present-day practice. The current study was carried out single centre. Yet, as a tertiary referral centre for post radical orchiectomy follow up and treatment respondents have been primarily counselled and operated all over the region of south-west Netherlands. Consequently, our sample is expected to be representative of the surrounding peripheral hospitals as well. At 35.5%, the response rate was reasonable for a paper survey, and may have been influenced by the time from diagnosis until the survey, survey length and sensitivity of the subject (fertility concerns) [30]. However, including a sample of 201 respondents, results have to be interpreted with caution. With a significantly longer follow up time among responders vs. non-responders, it may possibly be assumed after a longer period of time the subject of fertility is more easy to reflect on for survivors.

Despite these limitations, this study is one of the first assessing TC survivors and their experience, opinions and satisfaction regarding the discussion of fertility issues and process of sperm cryopreservation. The current, relatively large sample provides us with useful insights for current practice, including preferred health care provider for counselling, satisfaction levels and the lack of provision of written information materials. Moreover, it implicates the need for further calling attention to the timely discussion of fertility preservation in TC patients among health care providers, specifically urologists. This is supported by a recent study where a cancer and fertility program was established in a large cancer centre, including clinician education, provision of resources and consultations with a fertility clinical nurse specialist. Patient satisfaction among men was significantly improved and information material was found to be particularly helpful [28]. A prospective, longitudinal study could assist in answering remaining questions regarding specific fertility concerns arising at the time of diagnosis, preferred information resources (digital; written, verbal, etc.) and whether we will meet improved reproductive outcomes in the case of sperm cryopreservation in advance of orchiectomy. Furthermore, locations for sperm collection could be improved or be facilitated at a location according to the patient's preference more often.

## CONCLUSIONS

Findings of this testicular cancer patients survey indicate the importance of timely discussion of fertility issues. While being discussed with most men, several TC survivors reported not having received fertility counselling or counselling with limited information. Furthermore, counselling

was not always performed before orchiectomy, which is well known to negatively influence sperm sample quality. Dissatisfaction and grief may occur as a result of impaired fertility and a lack of support from healthcare providers. Overall, 6.5% made use of cryopreserved sperm, more than half of these patients achieved parenthood. Men prefer their urologist to provide information on fertility preservation. Satisfaction regarding the information offered about fertility issues varied and there was a relative lack of written information materials, indicating room for improvement in information provision.

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# Chapter 12

*Sexual and fertility-related adverse effects  
of medicinal treatment for cancer; a national  
evaluation among medical oncologists*

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## INTRODUCTION

Advances in diagnostic techniques and therapies have improved the survival rates of patients with different cancer types. As a result, the focus in healthcare has expanded from survival to long-term quality of life. Therefore, specialists' knowledge about the effects of therapy on fertility and sexual functioning is essential [1–3]. With 11,7000 cancer cases in the Netherlands in 2019, over 7000 of all invasive cancers are diagnosed in adults of reproductive ages [4]. Therefore, for cancer patients, but especially for patients of reproductive age, attention must be paid to sexual functioning and fertility before, during and after cancer treatment.

Sexual dysfunction is a common problem among men and women facing cancer and cancer treatments. Prevalence of sexual dysfunction depends on the type of cancer and treatment, ranging from 28 to 70% [5–10]. Multiple variables may contribute to sexual dysfunction, including hair loss, psychological impact, body image, fatigue, surgery and hormonal changes with consequences such as dry mucous membranes. In men, the most common sexual complaints associated with chemotherapy are decreased desire and erectile dysfunction. For example, platinum-based chemotherapy can lead to nerve damage, resulting in erectile dysfunction and anejaculation [11–13]. Loss of sexual desire and vaginal dryness are most commonly seen in women [11, 12]. One study performed by Baumgart et al. found dyspareunia in 57% of women with breast cancer using aromatase inhibitors. In 31% of women using tamoxifen, compared to 9–21% of age-matched controls [14].

Gonadal dysfunction caused by chemotherapy is a risk factor for decreased fertility in men and women [15]. The effects of chemotherapy on fertility depend on several factors like age, sex and chemotherapeutic regime. In women, treatment with chemotherapy may cause amenorrhea, premature ovarian failure and early menopause [11, 16]. In men, treatment with cytotoxic chemotherapy is associated with significant gonadal damage and impaired spermatogenesis. Germinal epithelial damage can result in temporary or permanent oligo- or azoospermia. Alkylating agents and platinum compounds are likely to cause infertility due to gonadotoxic effects [17, 18]. For men and women undergoing cytotoxic chemotherapy, several options for preserving fertility exist [18, 19]. These fertility preservation (FP) methods are often experienced as being invasive and distressing. Hence patients may experience psychological complaints such as depression and anxiety. Contrastingly, when persons are deprived of their chance of FP when their fertility is at risk of being impacted, this may cause even more grief and psychological issues [20]. Fertility counselling and pursuing fertility preservation is known to be associated with less regret and greater quality of life [21].

Despite the generally known impact of potential toxic cancer drugs on fertility and sexual function, it is still expected that patients do not receive fertility or sexual counselling by healthcare providers [22–24]. The percentage of patients who reported being uninformed about potential infertility due to cancer treatments varies from 0 to 85% [25, 26]. In previous studies, physicians have indicated various reasons for the lack of discussing fertility and sexual

problems [27–29]. Clinicians described unfamiliarity with fertility preservation, lack of confidence in abilities, lack of agreement with guidelines and fertility preservation and uncertainty about outcome expectancy as barriers to discuss [27]. In the Netherlands, most oncologists see oncofertility or sexual counselling as their responsibility, but it is discussed often or always by only 68.3% according to self-reported practice [30]. Only a minority of Dutch oncologists (18.5%) discussed sexual function regularly [31]. Other surveys mentioned a lack of knowledge regarding the adverse effects of cancer drugs and possible ways to prevent or treat them [28, 29]. However, no studies specifically describe which knowledge is available among oncologists.

The primary aim of this study was to explore medical oncologists' knowledge of the adverse effects of commonly used cancer drugs regarding their effect on fertility and sexual function. Additionally, the relationship between this knowledge and characteristics such as years of experience and frequency of prescription drugs was evaluated. Knowledge of oncologists with breast cancer, gynaecological and urological malignancies as areas of expertise has been separately evaluated, as many patients suffering from breast cancer or testicular cancer are in reproductive age [4, 32, 33]. Furthermore, we aimed to examine if being involved with cancer of the (internal) genital tract is a factor for improved knowledge of sexual and fertility-related adverse effects.

## METHODS

### Study design and cohort identification

A questionnaire was used for collecting data in a cross-sectional postal survey. The sample consisted of all 433 members of the Dutch Society for Medical Oncology (NVMO) with several areas of expertise. The inclusion criteria were being a practising medical oncologist in the Netherlands. All members were requested to provide information concerning specific tumour expertise, employment setting, education level, years of oncology experience, type of hospital, age and gender.

### Instrument design and development

The questionnaire was developed by the authors. Cancer drugs and their possible sexual or reproductive related adverse effects were identified by checking all oncology guidelines, the Summary of Product Characteristics (SmPC) and Netherlands Pharmacovigilance Centre Lareb, in collaboration with a professor of Medical Oncology (SO) and a pharmacist/PhD-student in sexual adverse drug reactions (RG). The SmPC is a mandatory document in Europe for the registration of drugs, with drug information generally based on registration trials and is used by pharmacists and medical specialists. Lareb is the national pharmacovigilance centre that registers possible new adverse reactions of drugs. Information about most and least frequently used oncology drugs in the Netherlands was obtained via the GIPdatabank [34], a database

with Dutch health insurance data on the use of reimbursed drugs over 5 years. The content of the questionnaire was evaluated by four oncologists in an anonymous pilot study and modified using their feedback. The final version comprised a demographic sheet and a list of common cancer drugs with their possible influence on sexual function and future reproductive ability. Demographic data included professional background, experience in oncology practice, gender and age. Participants were provided with a list of cancer drugs and asked to indicate, using multiple-choice options, which cancer drugs may adversely affect sexual function and fertility. They were explicitly asked not to look up these potential effects in reference documents. Oncologists were able to mark the option 'I don't know' if they were unsure about possible sexual and fertility-related adverse effects of a specific drug. Furthermore, Likert-scale items measured practices, attitudes, the content of sexual and fertility counselling content, responsibility, need for education, and barriers regarding discussing sexual function and fertility issues. Our survey data concerning the discussion of sexuality and fertility issues were processed separately [30, 31].

## Survey administration

The questionnaires were sent to all medical oncologists who were a member of the NVMO in January 2013. Reminders were sent to non-responders in July, 2013 and January, 2014. In addition, an information letter concerning the study and a post-paid return envelope were added, as well as an opt-out possibility. Data were collected anonymously in order to limit self-reporting bias.

## Analysis

Data analysis was performed using SPSS (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp., USA). Demographic information and answers to the part of the survey that concerned medication were analysed using descriptive statistics. For all results, a distinction was made between answers regarding fertility and answers regarding sexual function. Adverse drug reactions were considered legitimate if reported in the SmPC text of the drug. Adverse effects on fertility and sexual function reported at Lareb were also included in the evaluation of the results. Observed differences between demographic information and specific answers were identified using the Pearson's Chi-Square test or Fisher's Exact Test (2-sided). P-values <0.05 were considered statistically significant. For further analysis, subgroups with oncologists who marked 'breast cancer', 'nephrology/urology' or 'gynaecology' as area of expertise were analysed separately. In addition, the group was divided into two almost equally sized groups according to experience: 10 years or less and more than 10 years of work experience. Answers for the five most prescribed oncolytics according to the GIP databank [34] were added up and divided into two groups: 'not once filled in that this medication has any negative effect' and 'filled in one or more times that this medication has a negative effect'. The same was done for the five least prescribed oncolytics.

### Ethical considerations

In the Netherlands, research that does not involve patients or interventions is not subject to approval from ethical boards. As the study did not concern any information recorded by the investigator so that subjects could be identified and as it did not compromise the study participants' integrity, no formal ethical approval was needed for this study.

## RESULTS

The survey was distributed among 433 oncologists, of which 209 returned the survey (48.3%). Notification of refusal was received from 48 oncologists. Reasons mentioned for not participating included lack of time, no interest, too many questions and too many surveys. Of the 209 returned surveys, 9 were returned to sender because practicing abroad, 26 oncologists were retired, and 6 were members of the society but not medical oncologists. These 41 did not meet the inclusion criteria, which decreased the eligible participants to 392. Of the returned questionnaires, 120 questionnaires had been almost fully completed. 15 of 120 questionnaires were excluded because important answers were missing. Another 5 questionnaires had a partly completed 'medication' section, but were used for analysis. Thus, 105 surveys of 392 practicing oncologists (26.8%) were analysed.

### Demographics

The mean age of the respondents was 45.1 years (range 30–64), 54.3% were female and 44.8% male. Most of the participating oncologists had breast cancer as area of interest (75.1%), other frequently mentioned areas of interest included colorectal, gynaecology and nephrology-urology, as depicted in Table 1.

**Table 1.** Demographic characteristics

Demographic characteristics of participating oncologists (n=105)	n (%)
<b>Age (years)</b>	
Mean 45,1 years (range 30-64)	
Age 30-40	44 (41.9%)
Age 40-50	26 (24.8%)
Age 50-60	24 (22.9%)
Age >60	10 (9.5%)
Unknown	1 (1.0%)

**Table 1.** Demographic characteristics (*continued*)

Demographic characteristics of participating oncologists (n=105)	n (%)
<b>Gender</b>	
Male	47 (44.8%)
Female	57 (54.3%)
Unknown	1 (1.0%)
<b>Oncology experience (years)</b>	
1-2	18 (17.1%)
3-5	26 (24.8%)
6-10	12 (11.4%)
11-15	17 (16.2%)
>15	30 (28.6%)
Unknown	2 (1.9%)
<b>Function</b>	
Oncologist	66 (62.9%)
Haematologist	9 (8.6%)
Resident oncologist	18 (17.1%)
Resident haematologist	12 (11.4%)
<b>Hospital type</b>	
University hospital	35 (33.3%)
District general teaching hospital	25 (23.8%)
District general hospital	39 (37.1%)
Categorical cancer hospital	3 (2.9%)
University hospital and district general hospital	2 (1.9%)
<b>Area of interest <sup>a</sup></b>	
Breast	79 (75.2%)
Colorectal	70 (66.7%)
Palliative care	52 (49.5%)
Gynaecology	46 (43.8%)
Nephrology and urology	48 (45.7%)
Haematology	28 (26.7%)
Lymphoma	27 (25.7%)
Head and neck	14 (13.3%)
Neuroendocrine	14 (13.3%)
Skin	8 (7.6%)
Sarcomas	8 (7.6%)
Lung	3 (2.9%)
Other	16 (15.2%)

<sup>a</sup> Most oncologists reported multiple areas of expertise

# Knowledge of fertility- and sexuality-related adverse effects of cancer drugs/therapy

Table 2 shows which drugs that are used in cancer therapy, were mentioned to have a negative effect on fertility, ovulation, spermatogenesis and sexual function according to 100–105 medical oncologists. Drugs of which 50% or more of oncologists marked ‘I don’t know’ whether these drugs negatively affect fertility, ovulation, spermatogenesis or sexual function, were chlormethine (n=73, 72.3%), aminogluthemide (n=65, 63.1%), interleukin-2 (n=62, 62.0%), cyproterone (n=55, 55.0%) and busulfan (n=51, 50.0%).

Drugs that were most often believed to negatively affect fertility were cisplatin (n=81, 80.2%), epirubicin (n=78, 78.0%), cyclophosphamide (n=80, 77.7%), doxorubicin (n=76, 76.0%) and anthracycline (n=78, 75.0%). For sexual adverse effects, most mentioned drugs were tamoxifen (n=67, 65.7%), GnRH-agonists (n=64, 63.4%), autologous stem cell transplantation (n=59, 57.8%), cisplatin (n=58, 57.4%) and epirubicin (n=57, 57.0%). Drugs that were believed not to harm fertility were herceptin (n=69, 67.6%), bisphosphonates (n=63, 60.6%), imatinib (n=55, 54.5%), rituximab (n=51, 50.0%) and 5-fluoruracil (n=47, 44.8%). For sexual function herceptin (n=66, 64.7%), bisphosphonates (n=61, 58.7%), imatinib (n=51, 50.5%), methotrexate (n=50, 49.0%), rituximab (n=50, 49.0%) and 5-fluoruracil (n=45, 42.9%) were noted not to be of harm.

# Differences between knowledge of oncologists with or without breast cancer, nephrology/urology or gynaecology as areas of expertise

Table 3 provides an overview of cancer drugs that can be prescribed as mono- or combination therapy in breast cancer. Total respondents varied between 98 and 103. About fertility and sexual function, answers of oncologists with breast cancer as an area of expertise were compared with oncologists without breast cancer as an area of expertise. No significant difference in answering was found between these groups with regard to fertility or sexual function. Concerning sexual function, in SmPC texts, sexual adverse drug reactions were registered for GnRH-agonists, megestrol, methotrexate and tamoxifen only. Among oncologists with breast cancer as area of expertise, 48 (63.2%) thought that GnRH-agonists could negatively affect sexual function and 28 (36.8%) believed it would not. Among oncologists without breast cancer as area of expertise, these percentages were 69.6% (n=16) and 30.4% (n=7), respectively. Megestrol was believed to negatively affect sexual function by 52.0% (n = 39) of oncologists with breast cancer as an area of expertise, as by 69.6% (n=16) of oncologists who had not. Among oncologists with breast cancer as area of expertise 27 (35.5%) thought that methotrexate could negatively affect sexual function and 49 (64.5%) believed it would not. Percentages within the group of oncologists without breast cancer as area of expertise were 29.2% (n=7) and 70.8% (n=17) respectively.

**TABLE 2 CANCER DRUGS/THERAPY AND THEIR BELIEVED EFFECT ON FERTILITY, OVULATION, SPERMATOGENESIS AND SEXUAL FUNCTION**

	Number of respondents*	Negative effect on fertility (% yes ; % no)	Negative effect on ovulation (% yes ; % no)	Negative effect on spermatogenesis (% yes ; % no)	Negative effect on sexual functioning (% yes ; % no)	I don't know
5 FluorUracil	105	36 (34.3%) ; 47 (44.8%)	31 (29.5%) ; 52 (49.5%)	41 (39.0%) ; 42 (40.0%)	38 (36.2%) ; 45 (42.9%)	22 (21.0%)
Aminoglutethimide	103	15 (14.6%) ; 23 (22.3%)	14 (13.6%) ; 24 (23.3%)	5 (4.9%) ; 33 (32.0%)	17 (16.5%) ; 21 (20.4%)	65 (63.1%)
Anthracycline	104	78 (75.0%) ; 20 (19.2%)	74 (71.2%) ; 24 (23.1%)	73 (70.2%) ; 25 (24.0%)	55 (52.9%) ; 43 (41.3%)	6 (5.8%)
Autologous stem cell transplantation	102	65 (63.7%) ; 13 (12.7%)	60 (58.8%) ; 18 (17.6%)	60 (58.0%) ; 18 (17.6%)	59 (57.8%) ; 19 (18.6%)	24 (23.5%)
Bisphosphonates	104	1 (1.0%) ; 63 (60.6%)	0 (0.0%) ; 64 (61.5%)	0 (0.0%) ; 64 (61.5%)	3 (2.9%) ; 61 (58.7%)	40 (38.5%)
Busulfan	102	38 (37.3%) ; 13 (12.7%)	32 (31.4%) ; 19 (18.6%)	37 (36.3%) ; 14 (13.7%)	19 (18.6%) ; 32 (31.4%)	51 (50.0%)
Chlorambucil	101	35 (34.7%) ; 19 (18.8%)	30 (29.7%) ; 24 (23.8%)	36 (35.6%) ; 18 (17.8%)	18 (17.8%) ; 36 (35.6%)	47 (46.5%)
Chlormethine	101	18 (17.8%) ; 10 (9.9%)	16 (15.8%) ; 12 (11.9%)	15 (14.9%) ; 13 (12.9%)	9 (8.9%) ; 19 (18.8%)	73 (72.3%)
Cisplatin	101	81 (80.2%) ; 10 (9.9%)	70 (69.3%) ; 21 (20.8%)	70 (69.3%) ; 21 (20.8%)	58 (57.4%) ; 33 (32.7%)	10 (9.9%)
Cyclophosphamide	103	80 (77.7%) ; 12 (11.7%)	71 (68.9%) ; 21 (20.4%)	73 (70.9%) ; 19 (18.4%)	52 (50.5%) ; 40 (38.8%)	11 (10.7%)
Cyproteron	100	22 (22.0%) ; 23 (23.0%)	15 (15.0%) ; 30 (30.0%)	21 (21.0%) ; 24 (24.0%)	30 (30.0%) ; 15 (15.0%)	55 (55.0%)
Doxorubicin	100	76 (76.0%) ; 16 (16.0%)	70 (70.0%) ; 22 (22.0%)	68 (68.0%) ; 24 (24.0%)	56 (56.0%) ; 36 (36.0%)	8 (8.0%)
Epirubicin	100	78 (78.0%) ; 13 (13.0%)	70 (70.0%) ; 21 (21.0%)	67 (67.0%) ; 24 (24.0%)	57 (57.0%) ; 34 (34.0%)	9 (9.0%)
Etoposide	101	66 (65.3%) ; 14 (13.9%)	52 (51.5%) ; 28 (27.7%)	54 (53.5%) ; 26 (25.7%)	44 (43.6%) ; 36 (35.6%)	21 (20.8%)
GnRH-agonists	101	53 (52.5%) ; 32 (31.7%)	63 (62.4%) ; 22 (21.8%)	41 (40.6%) ; 44 (43.6%)	64 (63.4%) ; 21 (20.8%)	16 (15.8%)
Herceptin (trastuzumab)	102	4 (3.9%) ; 69 (67.6%)	1 (1.0%) ; 72 (70.6%)	0 (0.0%) ; 73 (71.6%)	7 (6.9%) ; 66 (64.7%)	29 (28.4%)
Ifosfamide	101	71 (70.3%) ; 13 (12.9%)	60 (59.4%) ; 24 (23.8%)	62 (61.4%) ; 22 (21.8%)	51 (50.5%) ; 33 (32.7%)	17 (16.8%)
Interferon-a	103	12 (11.7%) ; 43 (41.7%)	6 (5.8%) ; 49 (47.6%)	7 (6.8%) ; 48 (46.6%)	27 (26.2%) ; 28 (27.2%)	48 (46.6%)
Interleukine-2 (Aldesleukine)	100	7 (7.0%) ; 31 (31.0%)	4 (4.0%) ; 34 (34.0%)	5 (5.0%) ; 33 (33.0%)	16 (16.0%) ; 22 (22.0%)	62 (62.0%)
Imatinib	101	6 (5.9%) ; 55 (54.5%)	1 (1.0%) ; 60 (59.4%)	2 (2.0%) ; 59 (58.4%)	10 (9.9%) ; 51 (50.5%)	40 (39.6%)
Irinotecan	102	55 (53.9%) ; 25 (24.5%)	49 (48.0%) ; 31 (30.4%)	52 (51.0%) ; 28 (27.5%)	44 (43.1%) ; 36 (35.3%)	22 (21.6%)
Lomustine	100	35 (35.0%) ; 20 (20.0%)	32 (32.0%) ; 23 (23.0%)	32 (32.0%) ; 23 (23.0%)	20 (20.0%) ; 35 (35.0%)	45 (45.0%)
Megestrol	100	41 (41.0%) ; 40 (40.0%)	44 (44.0%) ; 37 (37.0%)	21 (21.0%) ; 60 (60.0%)	54 (54.0%) ; 27 (27.0%)	19 (19.0%)



TABLE 2 CANCER DRUGS/THERAPY AND THEIR BELIEVED EFFECT ON FERTILITY, OVULATION, SPERMATOGENESIS AND SEXUAL FUNCTION  
(continued)

	Number of respondents*	Negative effect on fertility (% yes ; % no)	Negative effect on ovulation (% yes ; % no)	Negative effect on spermatogenesis (% yes ; % no)	Negative effect on sexual functioning (% yes ; % no)	I don't know
Melphalan	100	54 (54.0%) ; 12 (12.0%)	42 (42.0%) ; 24 (24.0%)	49 (49.0%) ; 17 (17.0%)	27 (27.0%) ; 39 (39.0%)	34 (34.0%)
Methotrexate	102	53 (52.0%) ; 30 (29.4%)	46 (45.1%) ; 37 (36.3%)	49 (48.0%) ; 34 (33.3%)	33 (32.4%) ; 50 (49.0%)	19 (18.6%)
Platinum analogues	102	71 (69.6%) ; 17 (16.7%)	64 (62.7%) ; 24 (23.5%)	66 (64.7%) ; 22 (21.6%)	52 (51.0%) ; 36 (35.3%)	14 (13.7%)
Procarbazine	100	36 (36.0%) ; 18 (18.0%)	30 (30.0%) ; 24 (24.0%)	31 (31.0%) ; 23 (23.0%)	20 (20.0%) ; 34 (34.0%)	46 (46.0%)
Rituximab	102	3 (2.9%) ; 51 (50.0%)	1 (1.0%) ; 53 (52.0%)	1 (1.0%) ; 53 (52.0%)	4 (3.9%) ; 50 (49.0%)	48 (47.1%)
Tamoxifen	102	48 (47.1%) ; 44 (43.1%)	52 (51.0%) ; 40 (39.2%)	21 (20.6%) ; 71 (69.6%)	67 (65.7%) ; 25 (24.5%)	10 (9.8%)
Taxanes	102	71 (69.6%) ; 20 (19.6%)	62 (60.8%) ; 29 (28.4%)	69 (67.6%) ; 22 (21.6%)	51 (50.0%) ; 40 (39.2%)	11 (10.8%)
Vinblastine	100	43 (43.0%) ; 24 (24.0%)	33 (33.0%) ; 34 (34.0%)	43 (43.0%) ; 24 (24.0%)	30 (30.0%) ; 37 (37.0%)	33 (33.0%)
Vincristine	102	44 (43.1%) ; 28 (27.5%)	34 (33.3%) ; 38 (37.3%)	44 (43.1%) ; 28 (27.5%)	32 (31.4%) ; 40 (39.2%)	30 (29.4%)

\*nOT ALL RESPONDENTS ANSWERED EACH QUESTION  
Differences between knowledge of oncologists with or without breast cancer, nephrology/urology or gynaecology as area of expertise

TABLE 3 OVERVIEW OF ANSWERS OF ONCOLOGISTS WITH- AND WITHOUT BREAST CANCER AS AREA OF EXPERTISE REGARDING MEDICATION INDICATED IN BREAST CANCER THERAPY

	SmPC registered adverse effects (F=fertility, S=sexual function)	Total respondents* (breast cancer vs no breast cancer)	Oncologists with breast cancer as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	Oncologists who do not have breast cancer as an area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	P-value
5-FluorUracil	F: Spermatogenesis or ovulation disorder	103 (79 vs 24)	28 (35.4%) ; 51 (64.6%)	8 (33.3%) ; 16 (66.7%)	0.849
	S: No data is available on sexual function <sup>a</sup>		33 (41.8%) ; 46 (58.2%)	5 (20.8%) ; 19 (79.2%)	0.063
	F: Attenuation of spermatogenesis, ovulation disorder, amenorrhea, azoospermia, aspermia, oligospermia, oligomenorrhea	101 (77 vs 24)	62 (80.5%) ; 15 (19.5%)	18 (75%) ; 6 (25%)	0.561
Cyclophosphamide	S: No data is available on sexual function		42 (54.5%) ; 35 (45.5%)	11 (45.8%) ; 13 (54.2%)	0.456
	F: Risk of amenorrhea, oligospermia or azoospermia and risk of irreversible infertility	98 (75 vs 23)	56 (74.7%) ; 19 (25.3%)	19 (82.6%) ; 4 (17.4%)	0.432
	S: No data is available on sexual function		45 (60.0%) ; 30 (40.0%)	11 (47.8%) ; 12 (52.2%)	0.302
Epirubicin	F: In women: amenorrhea or premature menopause In men: damaged spermatozoa or irreversible infertility	98 (75 vs 23)	57 (76.0%) ; 18 (24.0%)	20 (87.0%) ; 3 (13.0%)	0.386
	S: No data is available on sexual function		46 (61.3%) ; 29 (38.7%)	11 (47.8%) ; 12 (52.2%)	0.251
GnRH-agonists	F: No data is available on fertility	99 (76 vs 23)	41 (53.9%) ; 35 (46.1%)	11 (47.8%) ; 12 (52.2%)	0.606
	S: Erectile dysfunction, vulvovaginal dryness, breast enlargement, loss of libido, gynecomastia, sore breasts		48 (63.2%) ; 28 (36.8%)	16 (69.6%) ; 7 (30.4%)	0.573
Herceptin (trastuzumab)	F: No data is available on fertility	100 (77 vs 23)	3 (3.9%) ; 74 (96.1%)	1 (4.3%) ; 22 (95.7%)	1.000
	S: No data is available on sexual function		6 (7.8%) ; 71 (92.2%)	1 (4.3%) ; 22 (95.7%)	1.000
Megestrol	F: Possible negative effect on fertility	98 (75 vs 23)	34 (45.3%) ; 41 (54.7%)	7 (30.4%) ; 16 (69.6%)	0.205
	S: Sore breasts, erectile dysfunction, loss of libido		39 (52.0%) ; 36 (48.0%)	16 (69.6%) ; 7 (30.4%)	0.138

TABLE 3 OVERVIEW OF ANSWERS OF ONCOLOGISTS WITH- AND WITHOUT BREAST CANCER AS AREA OF EXPERTISE REGARDING MEDICATION INDICATED IN BREAST CANCER THERAPY (continued)

	Smpc registered adverse effects (F=fertility, S=sexual function)	Total respondents <sup>a</sup> (breast cancer vs no breast cancer)	Oncologists with breast cancer as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	Oncologists who do not have breast cancer as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	P-value
<b>Melphalan</b>	<b>F:</b> In women, amenorrhea. In men azoospermia and risk of (ir)reversible infertility	98 (75 vs 23)	41 (54.7%) ; 34 (45.3%)	14 (60.9%) ; 9 (39.1%)	0.600
<b>Methotrexate</b>	<b>S:</b> No data is available on sexual function		24 (32.0%) ; 51 (68.0%)	4 (17.4%) ; 19 (82.6%)	0.175
	<b>F:</b> Defective oogenesis or spermatogenesis, infertility	100 (76 vs 24)	43 (56.5%) ; 33 (43.4%)	11 (45.8%) ; 13 (54.2%)	0.357
<b>Tamoxifen</b>	<b>S:</b> Inflammation or ulceration of vagina, gynecomastia, loss of libido, impotence		27 (35.5%) ; 49 (64.5%)	7 (29.2%) ; 17 (70.8%)	0.566
	<b>F:</b> Amenorrhea	100 (76 vs 24)	36 (47.4%) ; 40 (52.6%)	11 (45.8%) ; 13 (54.2%)	0.895
<b>Taxanes</b> (paclitaxel, cabazitaxel, docetaxel)	<b>S:</b> Irritation of genitalia externa <sup>d</sup>		52 (68.4%) ; 24 (31.6%)	16 (66.7%) ; 8 (33.3%)	0.872
	<b>F:</b> Impaired fertility in animal studies	100 (76 vs 24)	53 (68.7%) ; 23 (30.3%)	17 (70.8%) ; 7 (29.2%)	0.919
<b>Vinblastine</b>	<b>S:</b> No data is available on sexual function		40 (52.6%) ; 36 (47.4%)	12 (50.0%) ; 12 (50.0%)	0.822
	<b>F:</b> Impaired fertility, aspermia	98 (75 vs 23)	31 (41.3%) ; 44 (58.7%)	13 (56.5%) ; 10 (43.5%)	0.200
<b>Vincristine</b>	<b>S:</b> No data is available on sexual function		26 (34.7%) ; 49 (65.3%)	5 (21.7%) ; 18 (78.3%)	0.243
	<b>F:</b> Infertility, azoospermia, amenorrhea	100 (76 vs 24)	31 (40.8%) ; 45 (59.2%)	13 (54.2%) ; 11 (45.8%)	0.250
	<b>S:</b> No data is available on sexual function		27 (35.5%) ; 49 (64.5%)	7 (29.2%) ; 17 (70.8%)	0.566

<sup>a</sup>Two respondents who completed the medication part, didn't choose their areas of interest, so they were excluded from this analysis

<sup>b</sup>According to Lareb, the following adverse effects were reported for 5-fluorouracil: impotence(1x), vaginal / vulvar erosion(2x), vulvovaginal burning sensation(1x)

<sup>c</sup>According to Lareb, the following adverse effect was reported for tamoxifen: absence of menstruation (1x)

<sup>d</sup>According to Lareb, the following adverse effects were reported for tamoxifen: vulvar problems (3x), vaginal dryness (1x), vulvovaginal inflammation (1x) and pruritus (2x), itch (1x), dyspareunia (1x), impotence (1x) etc.

Tamoxifen was believed to negatively affect sexual function by oncologists with breast cancer as an area of expertise, as by oncologists who had not (68% and 67%). The same applied for fertility (47% and 46%). Cancer-specific drugs which are indicated for advanced or non-advanced forms of testicular cancer according to the SmPC texts are listed in Table 4. The total number of respondents varied between 98 and 99 oncologists. Concerning fertility and sexual function, answers of oncologists with 'nephrology/urology' as area of expertise were compared with oncologists who do not have 'nephrology/urology' as an area of expertise. Estimations of which cancer drugs negatively affect fertility or not were similar between these two groups. No significant difference in answering was seen concerning fertility, but a significant difference was seen in answering with regard to sexual function. Oncologists with 'nephrology/urology' as area of expertise estimated more often that these drugs negatively affect sexual function, in comparison to oncologists who did not have 'nephrology/ urology' as area of expertise (Cisplatin 68.9% vs 48.1%, Etoposide 57.8% vs 35.2%, Ifosfamide 66.7% vs 38.9%, Vinblastine 50.0% vs 16.7%). Table 5 provides an overview of cancer drugs that can be prescribed as mono- or combination therapy in ovarian cancer. The total number of respondents varied between 98 and 101. A significant difference in answering was only seen for melphalan concerning sexual function. Melphalan was believed to negatively affect sexual function by 17 (39.5%) oncologists with gynaecology as area of expertise, compared to 11 (20.0%) oncologists who had not ( $p=0.034$ ). For all other drugs, no significant difference in answering was seen with regard to fertility and sexual function.

## Years of experience

Findings regarding differences in answers related to years of oncology experience are listed in Table 6. Most oncologists ( $n=46$ , 88.5%) with 10 years or less of work experience estimated that at least one of the five most prescribed drugs could negatively affect fertility. This number was similar for oncologists with more than 10 years of work experience: 86.7% ( $n=39$ ). With respect to sexual function, 28.8% ( $n=15$ ) of oncologists with 10 years or less of work experience believed none of the five most prescribed medications can negatively affect sexual function in comparison to 37.8% ( $n=17$ ) of oncologists with more than 10 years of work experience. No significant difference was found between these groups when looking at the five most prescribed oncolytics (fertility  $p=0.789$ , sexual function  $p=0.351$ ) and the five least prescribed oncolytics (fertility  $p=0.986$ , sexual function  $p=0.461$ ).

TABLE 4 OVERVIEW OF ANSWERS OF ONCOLOGISTS WITH- AND WITHOUT NEPHROLOGY/UROLOGY AS AREA OF EXPERTISE REGARDING MEDICATION INDICATED IN TESTICULAR CANCER THERAPY

	SmPC registered adverse effects (F=fertility, S=sexual function)	Total respondents* (nephro/uro vs no nephro/uro)	Oncolegists with nephro/uro as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	Oncolegists who do not have nephro/uro as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	P-value
<b>Cisplatin</b>	<b>F:</b> Risk of irreversible infertility. Abnormal spermatogenesis	99 (45 vs 54)	37 (82.2%) ; 8 (17.8%)	43 (78.6%) ; 11 (20.4%)	0.744
<b>Etoposide</b>	<b>S:</b> No data is available on sexual function		31 (68.9%) ; 14 (31.1%)	26 (48.1%) ; 28 (51.9%)	0.038
	<b>F:</b> Possibly decreased fertility	99 (45 vs 54)	30 (66.7%) ; 15 (33.3%)	36 (66.7%) ; 18 (33.3%)	1.000
<b>Ifosfamide</b>	<b>S:</b> No data is available on sexual function		26 (57.8%) ; 19 (42.2%)	19 (35.2%) ; 35 (64.8%)	0.025
	<b>F:</b> Abnormal spermatogenesis, azoospermia, oligospermia, decreased levels of female sex hormones, amenorrhea	99 (45 vs 54)	32 (71.1%) ; 13 (28.9%)	39 (72.2%) ; 15 (27.8%)	0.903
<b>Vinblastine</b>	<b>S:</b> Sexual function and libido are usually not affected		30 (66.7%) ; 15 (33.3%)	21 (38.9%) ; 33 (61.1%)	0.006
	<b>F:</b> Decreased fertility, irreversible infertility, aspermia	98 (44 vs 54)	24 (54.5%) ; 20 (45.5%)	20 (37.0%) ; 34 (63.0%)	0.083
	<b>S:</b> No data is available on sexual function		22 (50.0%) ; 22 (50.0%)	9 (16.7%) ; 45 (83.3%)	0.000

\*Two respondents who completed the medication part, didn't choose their areas of interest and were thus excluded from this analysis

TABLE 5 OVERVIEW OF ANSWERS OF ONCOLOGISTS WITH- AND WITHOUT GYNAECOLOGY AS AREA OF EXPERTISE REGARDING MEDICATION INDICATED IN OVARIAN CANCER

	SmPC registered adverse effects (F=fertility, S=sexual function)	Total respondents* (gyn vs no gyn)	Oncologists with gynaecology as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	Oncologists who do not have gynaecology as area of interest. Negative effect on fertility or sexual function Yes (%) ; No (%)	P
Cisplatin	F: Risk of irreversible infertility. Abnormal spermatogenesis	99 (44 vs 55)	37 (84.1%) ; 7 (15.9%)	43 (78.2%) ; 12 (21.8%)	0.458
	S: No data is available on sexual function		27 (61.4%) ; 17 (38.6%)	30 (54.5%) ; 25 (45.5%)	0.495
Cyclophosphamide	F: Abnormal spermatogenesis, azoospermia, aspermia, oligospermia, ovulation disorder, amenorrhoea, oligomenorrhoea	101 (45 vs 56)	36 (80.0%) ; 9 (20.0%)	44 (78.6%) ; 12 (21.4%)	0.860
	S: No data is available on sexual function		26 (57.8%) ; 19 (42.2%)	27 (48.2%) ; 29 (51.8%)	0.339
Doxorubicin	F: Risk of oligospermia or azoospermia and risk of irreversible infertility	98 (43 vs 55)	31 (72.1%) ; 12 (27.9%)	44 (80.0%) ; 11 (20.0%)	0.359
	S: No data is available on sexual function		28 (65.1%) ; 15 (34.9%)	28 (50.9%) ; 27 (49.1%)	0.158
Etoposide	F: Possibly decreased fertility	99 (44 vs 55)	29 (65.9%) ; 15 (34.1%)	37 (67.3%) ; 18 (32.7%)	0.886
	S: No data is available on sexual function		23 (52.3%) ; 21 (47.7%)	22 (40.0%) ; 33 (60.0%)	0.223
Ifosfamide	F: Abnormal spermatogenesis, azoospermia, oligospermia, amenorrhoea	99 (44 vs 54)	29 (65.9) ; 15 (34.1%)	42 (76.4%) ; 13 (23.6%)	0.251
Melphalan	S: Sexual function and libido are usually not affected		25 (56.8%) ; 19 (43.2%)	26 (47.3%) ; 29 (52.7%)	0.345
	F: In women amenorrhoea. In men azoospermia and risk of (ir)reversible infertility	98 (43 vs 55)	26 (60.5%) ; 17 (39.5%)	29 (52.7%) ; 26 (47.3%)	0.444
	S: No data is available on sexual function		17 (39.5%) ; 26 (60.5%)	11 (20.0%) ; 44 (80.0%)	0.034

\*Two respondents who completed the medication part, didn't choose their areas of interest and were thus excluded from this analysis

TABLE 6 OVERVIEW OF ANSWERS OF ONCOLOGISTS WITH ≤ 10 YEARS OR > 10 YEARS OF EXPERIENCE REGARDING THE 5 MOST AND THE 5 LEAST PRESCRIBED ONCOLYTICS\*

Total respondents	Oncologists with ≤ 10 years of experience who not once filled in medication harms fertility	Oncologists with ≤ 10 years of experience who filled in one or more times that these medication has a negative effect on fertility	Oncologists with > 10 years of experience who not once filled in medication has a negative effect on fertility	Oncologists with > 10 years of experience who filled in one or more times that these medication has a negative effect on fertility	P-value
<b>5 most prescribed oncolytics</b> (cyclophosphamide, taxanes, rituximab, cisplatin, Herceptin)	97 6 (11.5%)	46 (88.5%)	6 (13.3%)	39 (86.7%)	0.789
<b>5 least prescribed oncolytics</b> (chlormethine, procarbazine, busulfan, doxorubicin, vinblastine)	96 8 (15.7%)	43 (84.3%)	7 (15.6%)	38 (84.4%)	0.986

Total respondents	Oncologists with ≤ 10 years of experience who not once filled in medication has a negative effect on sexual function	Oncologists with ≤ 10 years of experience who filled in one or more times that these medication has a negative effect on sexual function	Oncologists with > 10 years of experience who not once filled in medication has a negative effect on sexual function	Oncologists with > 10 years of experience who filled in one or more times that these medication has a negative effect on sexual function	P-value
<b>5 most prescribed oncolytics</b> (cyclophosphamide, taxanes, rituximab, cisplatin, herceptin)	97 15 (28.8%)	37 (71.2%)	17 (37.8%)	28 (62.2%)	0.351
<b>5 least prescribed oncolytics</b> (chlormethine, procarbazine, busulfan, doxorubicin, vinblastine)	96 20 (39.2%)	31 (60.8%)	21 (46.7%)	24 (53.3%)	0.461

\*Based on numbers from the GIPdatabank (34)

## DISCUSSION

This study was aimed to gain insight into the knowledge of Dutch oncologists in sexual and fertility-diminishing adverse effects of cancer drugs. According to our understanding, this study was the first to evaluate this knowledge. Results of this study revealed that oncologists have different beliefs about these effects. The lack of knowledge about adverse effects is consistent with results from other surveys. This gap in knowledge may be the reason that adverse effects of cancer drugs leading to infertility or sexual dysfunction are not often discussed in clinical practice [22–24, 27–29, 31].

According to our results, awareness among oncologists could be further improved concerning possible fertility-related adverse effects of cancer drugs, as many oncologists misestimated this or filled in they were unsure about adverse effects. For example, most oncologists estimated correctly that drugs like cisplatin (80.2%), cyclophosphamide (77.7%) or doxorubicin (76.0%) may negatively affect fertility. However, percentages were lower when looking at drugs such as chlorambucil (34.7%), busulfan (37.3%), procarbazine (36.0%) and vinblastine (43.0%). More remarkable was that 33–51% of oncologists indicated they did not know anything about the effects on fertility of these drugs, even though both SmPC texts and literature state that all of these agents may negatively affect fertility [16, 35]. Given that a significant number of oncologists made incorrect estimates or indicated they were unaware, this may also have consequences for discussing FP options and referral to fertility specialists. Another part of our nationwide survey was used to identify practice behaviour and attitudes of medical oncologists regarding fertility preservation [30]. Dutch oncologists considered discussing fertility as their responsibility, but in practice discussing fertility is influenced by a number of barriers such as prognosis and type of hospital. Half of the respondents declared to possess sufficient knowledge regarding fertility preservation ( $n=57$ , 47.5%). However, only 68.3% of oncologists indicated discussing the subject often or always [30]. Findings by Covelli et al., who performed a qualitative study to evaluate clinicians' barriers to discussing infertility and fertility preservation, suggest insufficient education and collaboration between fertility specialists and oncologists [27].

For each drug, at least one oncologist believed sexual complaints were associated with the drug treatment. In general, oncologists' opinions differed per drug: For some drugs, only 2.9% (bisphosphonates) and 3.9% (rituximab) of oncologists believed there could be potential sexual adverse effects. For other drugs, 63.4% (GnRH agonists) and 65.7% (tamoxifen) of oncologists believed sexual adverse effects were possible. It will remain unclear whether oncologists just picked available options or if their answers were based on their knowledge and experience in the clinic. Indeed, in literature and SmPC texts, GnRH agonists and tamoxifen are reported to increase the risk for sexual dysfunction [9, 14]. For example, the SmPC text of triptorelin, a gonadotropin agonist, estimated that 30–40% of men and more than 10% of women would be affected by sexual complaints [36, 37]. Sexual activity (including kissing, caring and self-masturbation) had changed for more than 70% of men and women after cancer



treatment [12]. From the literature, it is known that high dose chemotherapy can induce loss of desire for sex and trouble feeling aroused for men and women.

Moreover, neurotoxic chemotherapy (e.g. platinum compounds) can also induce erectile dysfunction in men and chemotherapy, in general, can cause abrupt, premature ovarian failure, leading to genitourinary atrophy, dryness, and pain in men women [9, 13]. However, most profoundly for drugs that can be considered chemotherapy, these effects are not often mentioned in SmPC texts. These omissions in the SmPC, maybe the explanation for a relatively low amount of oncologists being aware of possible sexual adverse effects of chemotherapy.

Another part of our survey also evaluated the discussion of sexual function, showing that the risk of sexuality-related adverse effects is barely discussed during informed consent conversations between Dutch oncologists and their patients [31]. Over 84% of participants stated having little or no knowledge of possible sexual adverse effects, 36% of oncologists considered lack of knowledge as a reason for avoiding discussion about sexual function. Regardless of their knowledge, over 72% of participants would like to acquire more training in counselling about sexual function [31].

In the current study, oncologists with breast cancer as an area of expertise had the same beliefs about the possible negative effects of cancer drugs on fertility and sexual function as oncologists without breast cancer as area of expertise. Interestingly, over 31% of the oncologists believe tamoxifen has no adverse effect on sexual function, while both SmPC texts and literature state the opposite [14, 38, 39]. According to different studies, tamoxifen users can experience reduced sexual interest (32–44%), dyspareunia, vaginal dryness and/or insufficient lubrication (30–40%) and orgasmic dysfunction (42%) [14, 38, 39].

Oncologists with ‘nephrology/urology’ as area of expertise marked significantly more often that cancer medication prescribed for testis malignancies may negatively affect sexual function (50–68.9%) in comparison to oncologists with other areas of expertise (16.7–48.1%). With no other explanation available, we hypothesise that oncologists with ‘nephrology/urology’ as area of expertise are more aware of sexuality because of involvement of the external male genitalia in testicular cancer and the relatively young age of affected men. For drugs, they often prescribe, no information is available in the SmPC texts on sexual function. However, articles are available in literature describing negative effects on sexual function from treatments such as cisplatin, etoposide, ifosfamide and vinblastine [13, 40]. A decrease in sexual activity (34%), loss of desire (25%) and ejaculation disorder (28%) was reported among patients treated for testicular cancer with chemotherapy [41]. With regard to oncologists with gynaecology as an area of expertise, we also hypothesised that they should be more aware of sexual and fertility-related adverse effects because of the involvement of the genital tract in ovarian cancer. However, with a single exception, no significant differences were seen in answering compared to the oncologists without gynaecology as an area of expertise.

Finally, when evaluating the results regarding the work experience of oncologists, one finding stands out in particular. For both the five most- and least prescribed oncolytic drugs,

oncologists seemed to be more aware of fertility than sexual function. Varied reasons could explain the difference between fertility and sexuality knowledge. In the SmPC, the official drug information leaflet, fewer sexual adverse drug reactions are registered than are known from the literature. In registration trials, patient self-reporting methods are often used to collect information on 'non-critical adverse drug reactions, which can lead to underreporting and under-registration of sexual adverse effects. Bonierbale et al. illustrated this difference reporting sexual adverse drug reactions in a study among 4557 depressive patients when evaluating spontaneous reports on sexual adverse drug reactions (35%) and when physicians specifically asked for sexual adverse drug reactions (69%) [42]. Another potential reason is that healthcare professionals might assume that sexual function is not essential when patients are facing life-threatening diseases such as cancer. Almost 45% of oncologists indicated they do not discuss sexual function if they believe the patient is too ill [31].

Another interesting finding is that no significant difference is seen between years of work experience and the estimated possible negative effect of oncolytic on fertility and sexual function. A study conducted among oncologists by Adams et al. found no significant differences in knowledge of FP by seniority or years in service [43]. Furthermore, no significant difference is seen between oncologists' clinical experience and a 'confidence in knowledge' score in regards to fertility issues, shown in a study performed by Louwe et al. [44]. Altogether, these results indicate that years in service do not seem to influence knowledge of fertility-related subjects, demonstrating there is room for education among oncologists from all levels of experience.

Our study should be interpreted with acknowledgement of its limitations. First of all, a non-validated postal survey was used for this study. This possibly led to selection bias, as oncologists who were more interested in subjects of fertility and sexuality were possibly more willing to participate. Also, one could assume that oncologists with at least some knowledge of adverse effects participated. The results may not directly reflect the clinical reality and may even be worse. Participants were asked not to look up adverse effects of cancer drugs evaluated in our survey as stated in the questionnaire. However, it will remain unknown whether oncologists have indicated what they thought or whether information has been searched for. Since the questions contained multiple choice answers, oncologists may have guessed correct answers. As the survey was executed in 2014, results may not apply to the current situation. Additional knowledge may have been obtained in the past few years, with growing public attention for the subjects fertility and sexual function. However, not much has been added to the literature and reference documents regarding specific sexual and fertility-related adverse effects. Therefore, the authors believe that this omission is probably negligible.

Based on the results of this survey, it can be concluded that the knowledge of oncologists is lagging what is known in literature and SmPC texts about fertility and sexuality-related adverse effects and needs to be optimised to some extent. Overall, findings from this study, supported by findings from the additional two studies based on our nationwide survey [30, 31] suggest that more awareness is needed about sexual and fertility-related adverse effects

of cancer treatments. Strategies for creating more awareness among oncologists have to be investigated and regular routines in practice that can provide patients with adequate information and counseling. Informing patients about possible adverse effects can contribute to the quality of life of cancer patients and survivors. This study also highlights the need for more broadly available extensive information regarding sexual and fertility-related adverse effects of commonly prescribed cancer drugs. Additionally, more attention should be paid to this topic in medical school or during residency and practicing as an oncologist.

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# PART III

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## Discussion and Summaries

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# Chapter 13

*General discussion and future perspectives*



## GENERAL DISCUSSION AND FUTURE PERSPECTIVES

The impact of cancer and its treatments on a person's sexual and reproductive function has been deliberated on to a great extent in existing literature. With the studies presented in this thesis, we aimed to make a step forward in identifying current practice and barriers in discussing sexual functioning and fertility concerns in medical and surgical oncology in the Netherlands. A retrospective Canadian study of medical records from cancer survivors of childbearing age showed a significant association between reproductive and sexual health counselling. Those who engaged in a dialogue around one topic were significantly more likely to be counselled by their medical provider about the other (1). This finding emphasizes the coherence between the two main subjects of this thesis, the counselling of sexual and reproductive health in oncology practice.

### **Part I Sexual health communication between cancer patients and oncology clinicians**

The first part of this thesis demonstrated the existing obstacles among the majority of the surveyed respondents in discussing sexual adverse effects and function during daily practice. In general, among oncology health care providers in the Netherlands, consensus exists regarding responsibility for addressing (potential) sexual dysfunction pre- and post-treatment. Despite this sense of responsibility, the implementation of discussing sexual function as a standard of care is not carried out structural. Knowledge regarding how to initiate a discussion concerning sexual function, how to treat sexual dysfunction and possible adverse effects of anti-cancer drugs is limited, and a need for training is expressed by a significant number of nurses and physicians. Furthermore, referral possibilities, patient information materials and department protocols seem to be lacking; updates could benefit both patients and medical professionals in daily practice.

#### ***Common barriers, factors influencing practice patterns and existing opinions***

In the surveys described in part one, the common failure of clinicians and nurses to address sexual health concerns of cancer patients is apparent. Assessments of sexual function are not regularly performed by health professionals in the clinical oncology setting. By identifying barriers for addressing sexual function, strategies could be accomplished to resolve current barriers keeping clinicians from providing sexual health care. Most mentioned barriers among Dutch oncology care providers were lack of training and lack of time, no angle or motive for initiating a discussion, advanced age of patients, presence of a third party and too ill patients. In comparison to literature, similar obstacles were found among health professionals discussing sexual issues with cancer patients, although cultural differences can be identified. In our surveys, lack of time was a repeatedly mentioned limitation in relation to the counselling on sexual function. In a qualitative study from White et al. among patients, partners and health

professionals performed at two cancer centres in the UK, time restraints were mentioned as well by both patients and health professionals (2). Both real and perceived time constraints existed, like patient workload and attitudes of health professionals during consultations. Health professionals considered addressing sexual function to be more time consuming because of its sensitive nature and time needed to determine the individual context for clinical intervention (2).

A lack of training was one of the most mentioned barriers among the variety of disciplines that were evaluated. Besides, a wish for additional training was expressed by a significant number of respondents from all evaluated professions. It was a general agreement that sexual counselling should be a regular component of medical speciality residency training in the field of oncology as well. However, the effect of educational training for oncology health care providers remains debatable. Grondhuis Palacios et al. evaluated the effect of a symposium on sexual health care in prostate cancer, but found no significant influence on knowledge, competence and referral rate after the symposium (3).

In contrast to a study performed by Faulder et al., which showed that teaching peer-led sex education improved medical students' confidence in dealing with sexual issues (4). The study conducted by Jonsdottir et al. depicted that a two year educational intervention for healthcare professionals resulted in higher knowledge scores and fewer perceived barriers. However, no significant reported changes in practice and frequency of discussing sexual issues were detected (5). In our surveys, self-reported knowledge relating to changes in sexual function during and after cancer treatment was limited as for most health professionals. In regards to adverse effects on sexual function of anti-cancer drugs, knowledge also seemed to vary widely. With a lack of training as the major barrier for counselling on sexual concerns, poor knowledge remains a factor that must be considered. In order to provide this component of care, awareness and knowledge of potential ramifications are indispensable.

Advanced age of patients as a barrier for bringing up sexual functioning is a rational barrier, though it should be reconsidered. In the survey of Lindau et al., among a sample of 3005 adults, sexual activity was reported by 73% among respondents who were 57 to 64 years of age, 53% among respondents who were 65 to 74 years of age, and 26% among respondents who were 75 to 85 years of age (6). Much as the prevalence of sexual activity declined with age, with a quarter of plus 75 years old reporting sexual activity, older adults' sexual function should not be neglected.

Other aspects were also demonstrated to influence current practice significantly. Younger aged respondents were less likely to discuss sexual function, likewise for less experienced professionals in the field of oncology and professionals with a self-reported lack of knowledge regarding sexual dysfunction. The presence of a department protocol addressing sexuality was also significantly influencing practice patterns. As for the surgical oncologists, men were more likely to discuss the topic. Male and older participants were also more likely to provide sexual

health care in a study performed in South Korea, which assessed oncology nurses' and physicians' attitudes relating to cancer patients (7).

On the subject of accountability for addressing sexual concerns in daily practice, the majority of all surveyed clinicians agreed that it is their responsibility to raise the matter (75-99%). This is with the exception of physicians working in the field of plastic surgery, of which 49.1% stated that plastic surgeons have the responsibility to discuss sexuality-related issues with their patients (however, most breast- and cosmetic surgeons agreed to their responsibility). Agreeance on responsibility for discussing sexual health with oncology patients was also seen among 94% of South Korean nurses and physicians (7). In a qualitative study performed in the Netherlands among patients, partners and health care professionals examining sexual health care needs in colorectal cancer care, health care professionals had a debate on whose responsibility it is to discuss sexual health (8). Patients and partners considered discussing sexuality a shared responsibility of health care professionals of each discipline, and possible consequences of their treatment should be discussed and evaluated during follow-up. Health care professionals assumed responsibility is an "and and" situation, meaning patients should feel free to ask questions regarding sexual health care if needed. They believed a professional network could intensify awareness that sexual health care is an essential aspect of cancer care (8). In general, oncology health care professionals feel responsible. However, translation to practice suggests that although a large amount of responsibility is felt for sexual concerns, responsibility for actually bringing up the subject is partly being left at the patients initiative.

### ***Coping with sexual concerns during and after cancer***

Late treatment effects in sexual functioning are prevalent among long-term cancer survivors and are strongly associated with reduced quality of life and high degrees of depression (9). Accordingly, it is of utmost importance for all involved clinicians to be aware of this overall burden and its impact. Strategies for dealing with sexual concerns during and after cancer treatment have been investigated widely and are still evolving continually. For many cancer patients seeking information becomes a convenient way of coping with a cancer diagnosis (10, 11). Accordingly, adequate information provision is an essential strategy for addressing sexual health as a part of integrative cancer care. Coping efforts frequently occur within the context of a relationship. They often include adjusting a couple's concept of sexual function and activity to behaviour that concentrates on intimacy and sexual activities rather than actual intercourse (a phenomenon called 'flexible coping') (12). Coping strategies for individuals have been researched less extensive in comparison to couple-based efforts (12). Psychosocial interventions were proven moderately helpful at improving sexual outcomes following cancer treatment (13). Physiological approaches may be helpful for specific indications, like vaginal dilator therapy for women after pelvic radiation, use of vaginal moisturizers or hormone replacement therapy for women who entered early menopause (14, 15). For men, physiological approaches may consist of the prescription of PDE5 inhibitors, vacuum constriction devices, intraurethral alprostadil,

intracavernous injections or penile prostheses (16). Online self-help intervention for sexual problems after cancer may also be an exciting option to explore. A recent study showed that an online intervention for women with cancer, including interactive cognitive-behavioural exercises, in-depth information for most cancer sites and guidance on finding professional help, led to increased sexual activity at follow up, improved sexual function, improved lubrication and decreased genital discomfort after three months (17). However, it is believed that men are less likely to search for health information on the internet and may also be less likely to utilize online health interventions (17-19).

### ***Closing the gap***

As a result of our efforts and commitment to create awareness for omissions in the current health care system regarding addressing sexual function, a variety of collaborations and initiatives have been carried out. To start with the establishment of the Sick and Sex foundation, an organization aiming for accessible healthcare in the field of sexuality, intimacy and relationship for anyone facing an illness (<http://www.sickandsex.nl>). The purpose of the foundation is to bridge the gap between care providers and patients. Scientific research is fundamental to the foundation's working method. The key feature is an informative website for both patients and clinicians and the development of informative apps plus videos addressing issues concerning disease and sexual functioning. We have heard from colleagues working all over the country that more and more care providers are finding their way to the Sick and Sex platform. Likewise, patients are easily referred to the website for additional information. Next, collaborations with the AYA network (established for adolescents and young adults with cancer), the Dutch Federation of Cancer patients (NFK) and several other specific cancer patient representative organizations have been established. These collaborations have resulted in the developments of a podcast ("De Besprekkamer"), an animated movie for partners of men with prostate cancer in collaboration with the Prostate cancer foundation (Prostaatkankerstichting), the development of the website <https://kankerenseks.nl> and the 'Pink Elephant' project (Roze Olifant). The Pink Elephant project is a toolbox developed for breast cancer care teams to discuss sexuality and intimacy with their patients (<https://www.seksinjegesprek.nl>). To resume, in the past few years, considerable efforts have been taken to create awareness on the subject of cancer and sexuality. Through all these collaborations, we feel a sense of optimism for the future, striving to further optimize sexual health care in oncology practice, above all for every person facing an illness.

### ***Recommendations for clinical practice***

Patients will scarcely express issues with their sexual functioning to a health care professional spontaneously. Hence, it is essential that sexual concerns are addressed in a routine, matter-of-fact approach. Factors within the institution, such as insufficient re-discussion of sexuality during follow-up consultations and inadequate referral systems, have been proven to impede sexual health care (8). As we have been able to demonstrate that the presence of a department

protocol addressing sexual health as a standard of care significantly influences practice patterns, it is recommended that every oncology practice incorporates sexual function as an item in its protocols. With a majority of our respondents expressing interest in educational training on sexual functioning and how to address it, providing training will undoubtedly be appreciated and raise awareness. Standardizations of informed consent provision with adverse effects of surgeries, radiation, and anti-cancer drugs mentioned, may help to improve information provision and contribute to patients' expectations management. In line with the informed consent provision, one can also consider implementing possible sexual side effects in treatment decision aids, which are increasingly used according to the shared decision-making developments in cancer care. Brief counselling could be provided by one specialized affiliated health professionals on an oncology treatment team, for example, a nurse specialist. A minority of patients will require specialized, intensive medical or psychological treatment for sexual concerns. In a large cancer centre, such treatment could be provided as part of a psychological recovery program serving the unique needs of cancer patients. In smaller settings, members of the oncology treatment team should build a referral network of specialists in the region.

During the compiling and progressing of the survey among oncologists about sexual adverse effects of cancer drugs, accessible information describing actual adverse effects to sexual function was not easy to uncover. This was substantiated by the considerably varying reported knowledge on adverse effects from our responding oncologists. A widely available overview of sexual side effects that may result from the admission of anti-cancer drugs would be beneficial.

### ***Future research***

A growing body of literature reveals the omissions in the current oncology practice regarding consideration of impaired sexual function as a result of cancer and its treatment. Although responsibility was felt, practice was highly varying and depending on multiple factors. The majority of our clinical working respondents expressed a wish for additional educational training. This conclusion could support new study designs to unravel the actual effect of different varieties of educational training for oncology health care providers. One has to bear in mind that educational programs may not be the solution for introducing sexual function into the daily oncology practice and other measures have to be taken to ensure necessary care will be incorporated in the future. For example, efforts to integrate sexual function into every practice by introducing access to sexologists or any other person who is comfortable in discussing sexual concerns may be more useful. Moreover, strategies on how to identify existing sexual concerns in a subtle way, the effect of screening patients who are at risk and the effect of offering sexual counselling routinely is yet to be evaluated. Empirical research should focus on how to manage information provision, counselling and follow up for sexual function disorders in cancer patients. A closer look to the specific needs of particular cancer types is recommended. Suitable guidance for partners is also to be evaluated. Particularly should be examined which coping strategies are effective for sexual concerns during and after cancer for both single patients



and couples of all ages. Research questions should specifically address how to offer targeted interventions and how to improve the current infrastructure about referral networks within organizations. However, the added value and efficacy of targeted interventions and specific infrastructure is still to be identified. The role of adequate information provided should not be underestimated. By this means, one can think of tailored information suiting a patients' level of understanding, literacy and preferred extensiveness. Some patients may profit more from digital apps and animated movies, others from personal counselling, stories of fellow sufferers or simply very factual, written information.

## **Part II Discussion of fertility concerns with cancer patients of reproductive age**

Part two of this thesis describes self-reported practice routines concerning the counselling on impaired fertility and the possibility of fertility preservation for patients of reproductive age facing cancer. Furthermore, for testicular cancer patients we reported on specific items concerning the discussion, referral and process of semen cryopreservation. Long term reproductive concerns were identified among these testicular cancer survivors. Lastly, knowledge of medical oncologists was evaluated regarding anti-cancer drugs side effects in relation to sexual function and reproductive capacity.

### ***Current practice, barriers, knowledge and responsibility***

Medical oncologists and oncology nurses both reported discussing the impact of cancer treatment on fertility. However, it was not performed in all cases and depending on several factors like educational level, working experience, type of hospital, patients' prognosis and chances of fertility recovery. The most important indicated reasons for not discussing fertility-related issues by medical oncologists were poor prognosis, unlikely survival of treatment and the high chance of fertility recovery after treatment. As for nurses, these reasons were a lack of knowledge, a poor prognosis and a lack of time during consultations. For both oncology team members, especially prognosis seemed to play a major role in whether or not to discuss the subject of fertility. This is comparable to the opinions from oncologists working in Sweden (20), Germany (21), Canada (22), the United Kingdom (23) and the United States (24). Instinctively, the prognosis seems an important factor in counselling about future fertility. However, one must remember that under certain circumstances, post-mortem reproduction using preserved semen, embryo's, oocytes or ovarian tissue is considered by either partners or family members (25). Therefore, even in the palliative setting, the subject should not be ignored. Half of the surveyed Dutch oncologists believed posthumous reproduction is acceptable; more than a third stated this should not be acceptable, and others were not aware of this possibility. Knowledge concerning fertility preservation options was limited among both nurses and medical oncologists. Three-quarters of the oncologists stated that current residency training is lacking education about fertility issues

and expressed a wish for additional training. Responsibility for discussing fertility issues was felt by the majority of oncology nurses (73%) and medical oncologists (93%).

### ***Information provision regarding impaired fertility and preservation options***

Self-reported practice of medical providers with regards to fertility counselling showed that 68.3% of medical oncologists and 32.3% of oncology nurses often or always discussed fertility issues with their patients. Referral to fertility specialists by medical oncologists was reported to be performed for 44.6% of reproductive men and 28.9% of reproductive women. A Canadian study retrospectively reviewed medical records of 427 patients aged 20-39 diagnosed with solid tumors between 2008-2010 who survived  $\geq$  two years. Records showed that only 58% received counselling on reproductive health at their initial oncology consultation, most of which were led by medical oncologists. By 6 months, an additional 7% had undergone counselling about fertility (1). Data imply that the lack of referral for reproductive issues in oncology practice is a worldwide matter.

In this thesis, referral was evaluated for semen preservation in male facing testicular cancer. Our results showed that 1 out of 10 men were not informed about possible impaired fertility, and the possibility of fertility preservation was mentioned according to 77% of the respondents. When comparing to literature, in a sample of 201 male cancer survivors, only 60% recalled being informed about infertility as a side effect of cancer treatment, and 51% had been offered sperm banking (26). The men who discussed infertility with their physicians possessed more knowledge about cancer-related infertility and were significantly more likely to bank sperm (26). Adequate information provision seems to be of major importance to make a decision about whether or not to bank sperm after being diagnosed with cancer. Among our sample of testicular cancer survivors, written information materials regarding fertility issues were provided in less than a quarter of the respondents. This corresponds to an American survey among oncologists, where only 13.5% reported 'always or often' giving their patients educational materials about fertility preservation (27). Development and the broad availability of educational materials are essential to facilitate communication between oncology care professionals and patients on this important topic.

For women, Bastings et al. showed that only 9.8% of all potential women (aged 0-39 years) were referred to a fertility specialist in 2011, although the absolute number of patients receiving fertility preservation counselling increased over time (28). Among a sample of 166 young women undergoing chemotherapy for breast cancer, 34% of women reported recalling a discussion with a physician regarding fertility (29). In a young adult female cancer survivor survey, 43% to 62% of participants reported an unmet information need regarding fertility topics (30). Given the rapidly expanding treatment options for fertility preservation in women facing cancer in the past decade, it is no surprise that physicians are not entirely familiar with all these options and women are often poorly informed. Besides patient educational materials, physicians also require regular updates on fertility preservation developments and availability

within their own clinic, region or country. This corresponds to oncologists stating that the topic is lacking in current residency, with an expressed need for additional training.

### ***Children born to cancer survivors***

One of the most significant reproductive concerns of cancer patients and survivors, concerns the health of future offspring (30). Although rare, unexpected health problems may occur during pregnancy due to damage to heart or lung function (31). Birth complications for female cancer survivors may include low birth weight infants, premature birth or miscarriage, particularly after pelvic radiation (32, 33). Congenital anomalies are not increased among either female or male cancer survivors' offspring (32, 34, 35). Children who have been exposed to chemotherapy in utero due to maternal cancer treatment are likely to be healthy unless chemotherapy was administered after the first trimester of pregnancy (36). Becoming pregnant after completing cancer treatment does not appear to enhance the possibility of recurrence, even in women with hormone-positive breast cancer (37).

### ***Psychosocial impact of fertility concerns among cancer survivors***

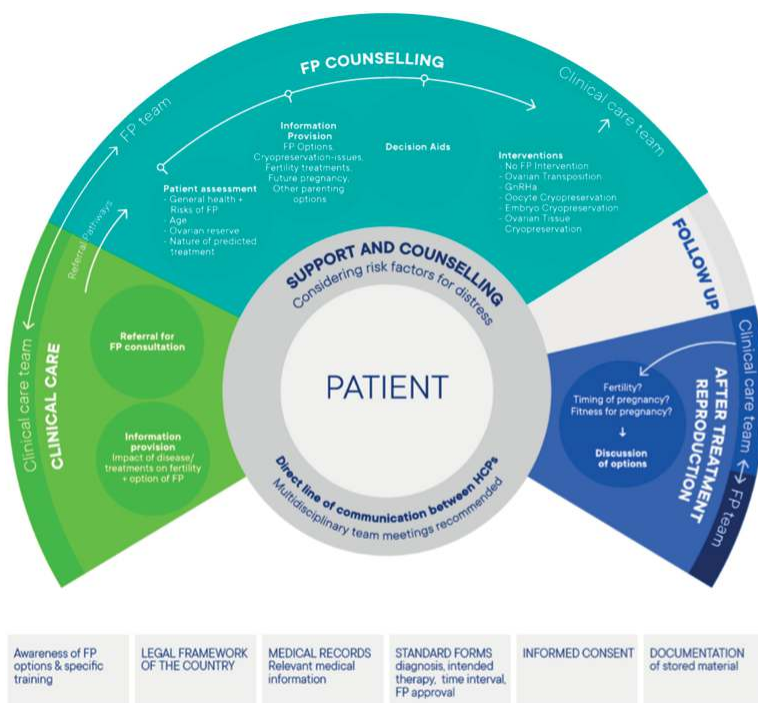
Several instruments have been developed to measure reproductive concerns of female cancer survivors, like the Reproductive Concerns After Cancer scale (RCAC) and the Reproductive Concerns Scale (RCS) (38, 39). The RCAC scale has also recently been modified for the use of male cancer survivors (RCAC-M scale) (40). The INDICATE data showed that long-term reproductive concerns, grief and less satisfaction in life occurred among men who survived testicular cancer. Correspondingly, a recent survey among testicular cancer survivors reported 28% of the sample had a high level of reproductive concerns in  $\geq 1$  dimension of the RCAC (41). In female cancer survivors, significant distress about infertility and avoidance is reported when reminded of infertility (42). Prevalence of reproductive concerns reported by women after cancer is much higher when compared to men (58-65% with moderate to high scores), and associated with severe depression (43, 44). Reproductive concerns are well known to be significantly associated with lower quality of life (39). Reproductive concern scales may help screen for concerns among cancer survivors of reproductive age and lead to a timely referral for psychosocial support.

### ***Recommendations for clinical practice***

A vital component of comprehensive care for cancer patients is addressing potential threats to their reproductive health. Referral for counselling about fertility preservation options is associated with less regret and greater quality of life (45). Men and women of reproductive age should receive expert counselling and should be given the opportunity to make active decisions about preserving fertility, despite their prognosis, partner status or possible treatment delay. Prompt referral to reproductive specialists allows patients to explore options for fertility preservation prior to the receipt of cancer-directed therapies. There is an urgent need for improvements in

oncology care to ensure all patients of reproductive age are well informed about infertility risks and fertility preservation options and to support them in their reproductive decision-making prior to treatment. Enhancing shared decision making has the potential to prevent later-life grief, unmet reproductive wishes and irreversible damage to reproductive organs. Oncofertility referral pathways should be implemented in every centre providing cancer care, with optimal collaboration between clinicians, nurses, psychologists and fertility departments. It is recommended that patients at risk are referred for psychological support when needed. In particular, patients with a history of psychopathology are at risk for psychological distress during fertility preservation decisions (46).

Improvements in patient and oncology clinician education, as well as coordinated referral within cancer care centres are crucial to secure fertility preservation as a priority pre-treatment. Figure 1 depicts a proposed model of care for patients eligible for fertility preservation, as extracted from the European Society of Human Reproduction and Embryology (ESHRE) female fertility preservation guideline. Interventions should be developed for cancer survivors in order to improve coping with unresolved grief due to cancer-related infertility. For medical oncologists, a comprehensive overview of fertility diminishing effects that may result from the admission of specific anti-cancer drugs would be advantageous.



**Figure 1.** Model of care for patients eligible for fertility preservation.

Source Preservation TEGGoFF, Anderson RA, Amant F, Braat D, D'Angelo A, Chuva de Sousa Lopes SM, et al. ESHRE guideline: female fertility preservation†. Human Reproduction Open. 2020;2020(4). (46).

### ***Future research***

Current literature demonstrates the need for and the limits of current fertility counselling in cancer care. Future research should mainly target methods to improve access to care by facilitating reliable referral pathways and decision-making processes for patients, survivors and oncology health professionals. Religious and cultural constraints, as well as costs and insurance issues, should be taken into account. Furthermore, existing uncertainties regarding the exact treatment risks of cancer-related infertility should be investigated. As our survey among oncologists showed, estimations of fertility impact from cancer drugs are highly variable and, in many cases, insecure.

With an expected increasing number of oncofertility practice due to the growing number of fertility preservation options, a corresponding increase of need for education will emerge. Incorporation of oncofertility education in medical school, residency and fellowship curricula should be undertaken. Furthermore, nurses, nurse practitioners and physician assistants can assist medical doctors in the process of counselling and referral for fertility preservation and should be involved in educational initiatives. With a proven, strong willingness to engage in educational activities among medical providers in the oncological community, we are urged to incorporate education. An example may be taken from the American Society for Reproductive Medicine's Air Learning platform, which created numerous educational tools in various formats, including a oncofertility textbook, educational training videos and a free online certificate course (47).

Research should be performed to identify optimal learning strategies, timing and content. Adequate patient information provision on fertility risks and fertility preservation options is identified as a critical component of oncofertility care, should be improved in quality and available in different formats (48). Scientific progress can be made in identifying optimal patient information services.

Psychological distress due to fertility concerns is prevalent and persistent in cancer patients and survivors. Virtually all patients and survivors would benefit from fertility-related psychological support implemented into standard practice from diagnosis through to survivorship. Instruments measuring reproductive concerns may be helpful in screening. Currently, there is a lack of studies examining these concerns in men diagnosed with cancer.

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# Chapter 14

## *Summary*



# INTRODUCTION

## Cancer and sexuality

Being confronted with a cancer diagnosis of any kind is a life-changing event, with major impact to well-being, quality of life and couple relationships. Cancer treatments and outcomes have dramatically improved in recent years, but have the potential to impair endocrine, reproductive and sexual function. For most cancer patients, sexual function is a proven, important aspect of quality of life, regardless of age and type of cancer. Among 41.2% of patients with one of the ten most commonly occurring cancers, sexual dysfunction is a concern approximately one year after being diagnosed. Sexual side effects are wide ranging and go beyond treatment of cancer of solely the pelvic or breast organs. Due to the increase in the number of cancer survivors, attention for cancer survivorship is increasing correspondingly. For most patients, cancer survivorship includes maintaining a satisfactory quality of life, along with the ability to sexually function appropriately. Nonetheless, for various reasons sexual function is frequently omitted and underreported by oncology health care professionals. Few cancer patients recall discussing possible sexual side effects before commencing their treatment, neither do they remember discussing treatment options for sexual issues after treatment. Coping with sexual concerns during and after cancer treatment seems to remain a delicate business for health care professionals, patients and their partners. A surge of literature has come up the past decade highlighting the importance of sexual function in cancer patients. To which amount consideration is paid to sexual concerns of cancer patients in the Dutch oncology practice remained unidentified so far and hence the incentive for this thesis.

## Fertility impairment due to cancer treatment

Cancer treatment may result in impaired fertility and influence family planning in patients of reproductive age (defined by the WHO as 15-49 years). Not only will various cancer treatments alter reproductive potential, in groups like testicular cancer and lymphoma patients, fertility may already be decreased before treatment has started. Female cancer survivors have 39% less chance of becoming pregnant compared with the general population. Future fertility perspectives are somewhat better in male survivors, with a 26% lower post cancer pregnancy rate in comparison with the general population. A variety of options has come available in the past decades, providing us with rapid and effective methods to cryopreserve gametes, embryos and reproductive tissue for patients about to commence cancer treatment. Several international guidelines, networks and foundations have been established in recent times, highlighting the importance of timely discussion of potential fertility deterioration resulting from cancer treatments. In spite of these developments, practice behaviour and attitudes of health care professionals have been reported to vary, influenced by several barriers to discussing this delicate subject with cancer patients of reproductive age. Among clinicians, knowledge of fertility preserving options and when they should be offered is suggested to be varying and

not always clear. A review regarding fertility concerns in cancer survivors mentioned a recall for counselling of fertility risks ranging from 34 to 72%. The long-term emotional impact of not being able to conceive a child is a serious source of distress to people treated for cancer during childbearing age. Loss of fertility is the most distressing long-term outcome of cancer treatment and linked with reduced quality of life and mental health issues. Counselling about reproductive loss and fertility preservation by not only the treating physician, but also a fertility specialist is associated with less regret and greater quality of life for cancer survivors. The intention emerged to investigate whether patients are well informed about infertility risks, fertility preservation options and if sufficient support is provided for guiding them in their reproductive decision-making prior to treatment. By assembling this knowledge from the perspective of both doctors, nurses and patients, recommendations can be composed for improvements in clinical care for this vulnerable group at risk of losing their reproductive capability.

## **Part I Sexual health communication between cancer patients and oncology clinicians**

### **Chapter 2**

#### ***Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses***

In most types of cancer, the disease and its treatment can result in altered sexual function (SF). Oncology nurses are strategically placed to address SF since they have frequent patient interaction. Our aim was to establish their knowledge about and attitudes to SF in oncology care and identify their perceived barriers to addressing the subject. A 37-item questionnaire was administered during the 2012 Dutch Oncology Nursing Congress and mailed to 241 Dutch oncology nursing departments. The majority of 477 nurses (87.6%) agreed that discussing SF is their responsibility. Discussing SF routinely is performed by 33.4% of these nurses, consultations mainly consisted of mentioning treatment side-effects affecting SF (71.3%). There were significant differences depending on experience, knowledge, age, academic degree and department policy. Nurses  $\leq 44$  years old ( $p < 0.001$ ), with  $< 10$  years oncology experience ( $p = 0.001$ ), insufficient knowledge ( $p < 0.001$ ), no academic degree ( $p < 0.001$ ), and in whose department policy was lacking or inadequate ( $p < 0.001$ ), were less comfortable discussing SF. Barriers included lack of training, presence of a third party and no angle or motive for initiating discussion. Findings suggest oncology nurses consider counselling on sexual issues to be an important responsibility, in line with discussing other side-effects caused by the disease or its treatment. Nevertheless, cancer patients may not routinely be receiving a sexual health evaluation by oncology nurses. Results emphasize the potential benefit of providing knowledge, including practical training and a complete department protocol.

## Chapter 3

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

Sexual function is an important factor in quality of life, but at risk after several surgical cancer treatments. Our aim was to identify the practice, responsibility, attitudes, knowledge and barriers of surgical oncologists towards providing informed consent on sexual side effects and sexual counselling. A 31-item questionnaire was sent to all 437 members of the Dutch Society for Surgical Oncology (NVCO). The majority of 165 responding surgical oncologists (85.5%) stated that discussing sexual function is their responsibility, 13.0% thought it to be somebody else's responsibility. During informed consent of a planned surgical procedure, sexual side effects are mentioned by 36.6% of surgeons in more than half of the cases. Counselling sexual function was performed by 9.2% of the surgeons in more than half of the cases. Older surgeons ( $\geq 46$  y) and male surgeons discuss sexual concerns more often ( $p = 0.006$  v  $p = 0.045$ ). Barriers most mentioned included advanced age of the patient (50.6%), not relevant for all types of cancers (43.8%), lack of time (39.9%) and no angle or motive for asking (35.2%). Additional training on counselling patients for sexual concerns was required according to 46.3%. In conclusion, surgical oncologists do not routinely discuss sexual concerns. Informed consent includes limited information about possible complications on sexual function. Surgeons consider themselves responsible for raising the issue of sexual dysfunction, but consider advanced age of patients, lack of time and no angle or motive for asking as major barriers. Results emphasize the need for raising awareness and providing practical training.

## Chapter 4

### ***Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist?***

Sexual function is an important aspect of quality of life, and may be impaired after (pelvic) radiation. The aim of this study was to identify practice, responsibility attitudes, knowledge, and barriers of Dutch radiation oncologists regarding sexual counseling. A cross-sectional survey was performed using a 28-item questionnaire sent to all members of the Dutch Society for Radiotherapy and Oncology. Of the surveyed sample, 54.6% of the radiation oncologists completed the instrument ( $n = 119$ ). Frequency of discussing sexual function was fluctuating, depending on the type of tumor. The majority of the responding radiation oncologists (75%) agreed that discussing sexual function is their responsibility, about one-third (33.6%) pointed at the involved specialist (surgeon, urologist, gynecologist, or oncologist), a fifth also considered the general practitioner responsible (21%). Additional training about discussing sexuality was required according to 44.4%, the majority agreed that sexual counseling should be a regular component of radiation oncology residency ( $n = 110$ , 94%). Barriers most mentioned included

patient is too ill (36.2%), no angle or reason for asking (32.4%), advanced age of the patient (27%) and culture/religion (26.1%). For prostate cancer patients, phosphodiesterase 5 inhibitor information was supplied regularly (49.2%) and often (40.7%). Radiation oncologists generally perform sexual counseling in case of pelvic radiation therapy, but not consistently in case of gastrointestinal, breast, and other cancers. The majority of radiation oncologists considered counseling on sexual functioning as a part of their job, some also pointed at the referring specialist or general practitioner. The findings suggest that awareness about sexual dysfunction is present among radiation oncologists, but responsibility for active counseling is uncertain. Results emphasize the need for providing educational and practical training, as well as a list for specialized referral.

## Chapter 5

### *Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges*

Sexuality is a significant quality-of-life concern for many cancer patients. Patients may be disadvantaged if they are not informed and not offered sexual health care. We sought to reveal oncologists' current practice and opinions concerning sexual counselling. The aim of this study was to explore the knowledge, attitude and practice patterns of Dutch medical oncologists regarding treatment-related sexual dysfunction. Questionnaires were sent to 433 members of the Dutch Society of Medical Oncology. The majority (81.5%) of the 120 responding medical oncologists (response rate 30.6%) stated they discussed sexual function with fewer than half of their patients. At the same time, 75.8% of the participating oncologists agreed that addressing sexual function is their responsibility. Sexual function was discussed more often with younger patients and patients with a curative treatment intent. Barriers for avoiding discussing sexual function were lack of time (56.1%), training (49.5%) and advanced age of the patient (50.4%). More than half (64.6%) stated they had little knowledge about the subject and the majority (72.9%) wanted to acquire additional training in sexual function counselling. Medical oncologists accept that sexual function counselling falls within their profession, yet they admit to not counselling patients routinely concerning sexual function. Only in a minority of cases do medical oncologists inform their patients about sexual side effects of treatment. Whether they counsel patients is related to how they view patient's prognosis, patient's age, and self-reported knowledge. Findings indicate there is a role for developing education and practical training.

## Chapter 6

### ***Omissions in Urology Residency Training Regarding Sexual Dysfunction Subsequent to Prostate Cancer Treatment: Identifying a Need***

The objective was to assess urology residents' current knowledge, practice, previous training, barriers, and training needs regarding prostate cancer treatment-related sexual dysfunction. A cross-sectional questionnaire study inventoried the practice patterns and training need of urology residents attending a national training course in June 2015. Of 101 urology residents throughout the Netherlands, 87 attended the training (response rate 100%). Median age was 32 years (range 28-38); 55.2% were woman. Regardless of the residency level, most trainees had never received education about sexual dysfunction (58.6%), reported a limited level of knowledge (48.3%), and indicated an evident need for training (69.4%). The majority did not feel competent to advise prostate cancer patients regarding the treatment of sexual dysfunction (55.2%). Almost all participants inquired about preoperative erectile dysfunction (89.7%), and always informed about treatment-related sexual dysfunction (88.5%). At follow-up, 63.9% of the residents routinely addressed sexual complaints again. More than half of the participants indicated that urology residency training does not provide sufficient education on sexual dysfunction (54.8%). Time constraint (67.1%) and lack of training (35.3%) were the most frequently mentioned barriers. Current urology residency does not pay sufficient attention to sexual communication skills and sexual dysfunction. The residents require more knowledge about and more practical training in sexual counseling. Findings support efforts to enhance the education of urology residents regarding prostate cancer treatment-related sexual dysfunction.

## Chapter 7

### ***Discussing sexuality in the field of plastic and reconstructive surgery: a national survey of current practice in the Netherlands***

Patient-reported outcomes have become increasingly important to assess the value of surgical procedures. Sexual function is a proven important constituent of quality of life, but is often overlooked by health care professionals. We aim to investigate to what extent plastic surgeons address or discuss issues concerning sexuality with their patients, and if there is a need for improvement. We developed a survey to assess whether topics pertaining to sexual function were discussed during plastic surgical consultations. In 2016, all 385 members of the Dutch Association for Plastic Surgery were invited via post mail to participate. We received 106 completed surveys (27.5%). The median age of the respondents was 45 (29-66) years. Most participants (78.3%) indicated that they rarely to never discuss sexuality with their patients. Surgeons in the sub specialization gender and genital surgery discussed sexual function most frequently. Two thirds of all respondents indicated that their current knowledge on this topic was insufficient, yet there was generally no interest expressed in receiving additional training



(78.6%). However, there was a need for proper patient brochures (43.4%) and an organized referral network (36.5%) regarding sexuality. In plastic surgery practice, sexuality appears to be a rarely discussed subject, with the gender and genital surgery subspecialties as the exception. Although professionals and patients emphasize the importance of sexuality, plastic surgeons express limited urge to be trained and prefer written patient information and referring patients to other healthcare professionals. The authors stimulate more education on sexuality during (continued) plastic surgery training.

## Chapter 8

### ***Written information material and availability of sexual health care for men experiencing sexual dysfunction after prostate cancer treatment: An evaluation of Dutch urology and radiotherapy departments***

The objective was to investigate content of written information material and availability of sexual health care for men experiencing sexual dysfunction (SD) after prostate cancer treatment. A cross-sectional survey was conducted among Dutch urology and radiotherapy departments to evaluate information materials and availability of sexual health care. Out of 71 eligible departments, 34 urology and 15 radiotherapy departments participated in the survey (response rate 69.0%). Fifty-nine brochures corresponding to 31 urology and 11 radiotherapy departments were analyzed. In 88.1% of collected information material, sexual health was mentioned. Regarding extensiveness, 20.4% of the brochures contained extensive information, 50.8% moderate amount of information and 28.8% contained little or no information. Urology departments provided pre-treatment nurse consultations more often than radiotherapy departments. Sexual counselling was more frequently provided by urology departments. Urology departments were more aware of adequate referral possibilities. Information material provided by Dutch urology and radiotherapy departments does not address treatment-related SD routinely. Sexual health care is not available everywhere for men experiencing SD. Applying a standard regarding content of sexual health in information material is recommended as well as improved awareness of referral possibilities and enhanced provision of pre-treatment nurse consultations for men experiencing SD after prostate cancer treatment.

## Part II Discussion of fertility concerns with cancer patients

### Chapter 9

#### ***Fertility preservation counselling in Dutch Oncology Practice: Are nurses ready to assist physicians?***

Cancer and its treatments may result in impaired fertility, which could cause long-term distress to cancer survivors. For eligible patients, fertility preservation (FP) is available to secure future

reproductive potential. Many physicians, however, feel inhibited about discussing FP. Oncology nurses may serve as an initiator for discussing the subject and provide additional support. Our aim was to investigate their knowledge about FP, the way they apply this, and possible barriers to discussing FP with patients of reproductive age. A questionnaire was administered via mail, Internet and the Dutch Oncology Nursing Congress. Four hundred and twenty-one oncology nurses participated, a third of whom (31.1%) had “sufficient” knowledge of FP. Twenty-eight per cent of participants reported that they “never/hardly ever” discussed FP; 32.2% “almost always/always.” FP discussions were more frequently performed by graduate nurses, academic nurses, experienced nurses and nurses with sufficient knowledge. Reasons for not discussing FP were a “lack of knowledge” (25.2%), “poor prognosis” (16.4%) and “lack of time” (10.5%). In conclusion, several obstacles may result in FP not being routinely discussed, specifically a lack of knowledge. Yet nurses feel responsible for addressing the issue, indicating that assistance with FP discussions should be encouraged. Educational training about FP is recommended.

## Chapter 10

### *An Educational Need regarding Treatment-related Infertility and Fertility Preservation; A National Survey among Members of the Dutch Society for Medical Oncologists*

Cancer diagnosis and treatment may influence reproductive planning and impact fertility in patients of reproductive age. Although guidelines have been established in the past decade, education, practice and attitudes of medical oncologists regarding fertility preservation remain undecided. A nationwide survey was performed among members of the Dutch Society for Medical Oncology. Demographics, practice, knowledge and barriers were measured regarding information provision of fertility preservation towards cancer patients of childbearing age. From 392 members, 120 oncologists completed the questionnaire (30.6%). Majority of oncologists was convinced it is their responsibility to discuss impact of cancer treatment to fertility (93.2%), yet 68.3% discussed the subject often or always (n=82). Oncologists employed in district general hospitals were less likely to discuss fertility (p=0.033). On average, 44.6% of reproductive men and 28.9% of reproductive women is referred to fertility specialists. Half of the respondents declared to possess sufficient knowledge regarding fertility preservation (n=57, 47.5%). Poor prognosis (53%), unlikely survival (43.1%) and high chances on fertility recovery (28.7%) were identified as barriers to discussing fertility preservation. Among oncologists, impact of cancer treatment on fertility is a well-accepted responsibility to counsel. Despite, self-reported knowledge regarding fertility preservation is strongly varying. In practice, fertility is discussed to some extent, influenced by several barriers and depending on prognosis and type of hospital. Patients benefit from knowledge improvement among oncology care providers concerning fertility effects of cancer treatment. Education during medical school, residency

and among practicing oncologists may raise awareness, together with enhancement of referral possibilities.

## Chapter 11

### ***Identifying the Need of Discussing Infertility Concerns Affecting Testicular cancer patients; an Evaluation (INDICATE study)***

Men with testicular cancer (TC) risk impaired fertility. Fertility is a major concern for TC patients due to diagnosis in almost always reproductive ages and high overall survival. This study assessed counselling in regards to the risk of impaired fertility and sperm cryopreservation. A cross-sectional survey was performed on 566 TC patients diagnosed between 1995-2015. Of the 566 survivors, 201 questionnaires were completed (35.5%). Eighty-eight percent was informed about possible impaired fertility, 9.5% was not informed. The majority (47.3%) preferred the urologist to provide information. Collecting sperm was troublesome but successful for 25.6%, 4.8% did not succeed in collecting sperm. The reasons were high pressure due to disease, pain after surgery and uncomfortable setting. Due to impaired fertility, 19% of the respondents reported grief and 9.3% stated as being less satisfied in life. Sperm cryopreservation was performed by 41.3% ( $n = 83$ ). One third ( $n = 63$ , 31.3%) had children after treatment, of which 11.1% made use of preserved sperm ( $n = 7$ ). The results of this survey indicate the importance of timely discussion of fertility issues with TC patients. While being discussed with most men, dissatisfaction and grief may occur as a result of impaired fertility and a lack of counselling. Overall, 6.5% made use of cryopreserved sperm ( $n = 13$ ). Men prefer their urologist providing counselling on fertility.

## Chapter 12

### ***Sexual and fertility-related adverse effects of medicinal treatment for cancer; a national evaluation among medical oncologists***

Anti-cancer drugs commonly adversely affect fertility and sexual function. Despite this, patients report a lack of counselling of these potential adverse effects. The aim was to determine Dutch oncologists' knowledge about the adverse effects of various cancer drugs on fertility and sexual function. A cross-sectional survey was sent to members of the Dutch Society for Medical Oncology ( $n=433$ ). The survey questions included various cancer drugs' adverse effects on fertility, ovulation, spermatogenesis, and sexual function. One hundred and five of 392 oncologists responded (26.8%). Oncologists were more aware of the adverse effects on fertility compared to sexual function. Drugs that were mostly believed to negatively affect fertility were cisplatin ( $n=81$ , 80.2%), epirubicin ( $n=78$ , 78.0%) and cyclophosphamide ( $n=80$ , 77.7%). Regarding sexual function, most mentioned drugs were tamoxifen ( $n=67$ , 65.7%), GnRH-agonists ( $n=64$ , 63.4%) and cisplatin ( $n=58$ , 57.4%). Oncologists with expertise in urology possessed more

awareness regarding sexuality-related adverse effects (cisplatin  $p=0.038$ , etoposide  $p=0.025$ , ifosfamide  $p=0.06$ , vinblastine  $p=0.000$ ). Results revealed that oncologists have different beliefs about possible sexual and fertility-related adverse effects concerning medication resources and literature. Based on our results, oncologists do not possess sufficient knowledge to inform patients about sexual and fertility-related adverse effects.

## DISCUSSION AND FUTURE PERSPECTIVES

With the studies presented in this thesis, we aimed to make a step forward in identifying current practice and barriers in discussing sexual functioning and fertility concerns in medical and surgical oncology in the Netherlands.

### **Part I Sexual health communication between cancer patients and oncology clinicians**

The first part of this thesis demonstrated the existing obstacles among the majority of the surveyed respondents in discussing sexual adverse effects and function during daily practice. In general, among oncology health care providers in the Netherlands, consensus exists regarding responsibility for addressing (potential) sexual dysfunction pre- and post-treatment. Despite this sense of responsibility, the implementation of discussing sexual function as a standard of care is not carried out structural. Knowledge regarding how to initiate a discussion concerning sexual function, how to treat sexual dysfunction and possible adverse effects of anti-cancer drugs is limited, and a need for training is expressed by a significant number of nurses and physicians. Furthermore, referral possibilities, patient information materials and department protocols seem to be lacking; updates could benefit both patients and medical professionals in daily practice. Assessments of sexual function are not regularly performed by health professionals in the clinical oncology setting. Most mentioned barriers among Dutch oncology care providers were lack of training and lack of time, no angle or motive for initiating a discussion, advanced age of patients, presence of a third party and too ill patients. It is recommended that every oncology practice incorporates sexual function as an item in its protocols. Providing training will be appreciated and raise awareness. Standardizations of informed consent provision with adverse effects of surgeries, radiation, and anti-cancer drugs mentioned, may help to improve information provision and contribute to patients' expectations management. Brief counselling could be provided by one specialized affiliated health professionals on an oncology treatment team, for example, a nurse specialist. A minority of patients will require specialized, intensive medical or psychological treatment for sexual concerns. A widely available overview of sexual side effects that may result from the admission of anti-cancer drugs would be beneficial. Future research focus should include study designs to unravel the actual effect of different varieties of educational training for oncology health care providers. Empirical research should

focus on how to manage information provision, counselling and follow up for sexual function disorders in cancer patients. A closer look to the specific needs of particular cancer types is recommended. Suitable guidance for partners is also to be evaluated. Particularly should be examined which coping strategies are effective for sexual concerns during and after cancer for both single patients and couples of all ages.

## **Part II Discussion of fertility concerns with cancer patients of reproductive age**

Part two of this thesis describes self-reported practice routines concerning the counselling on impaired fertility and the possibility of fertility preservation for patients of reproductive age facing cancer. Furthermore, for testicular cancer patients we reported on specific items concerning the discussion, referral and process of semen cryopreservation. Long term reproductive concerns were identified among these testicular cancer survivors. Medical oncologists and oncology nurses both reported discussing the impact of cancer treatment on fertility. However, it was not performed in all cases and depending on several factors like educational level, working experience, type of hospital, patients' prognosis and chances of fertility recovery. The most important reasons for not discussing fertility-related issues by medical oncologists were poor prognosis, unlikely survival of treatment and the high chance of fertility recovery after treatment. As for nurses, these reasons were a lack of knowledge, a poor prognosis and a lack of time during consultations. The INDICATE data showed that long-term reproductive concerns, grief and less satisfaction in life occurred among men who survived testicular cancer. Reproductive concern scales may help screen for concerns among cancer survivors of reproductive age and lead to a timely referral for psychosocial support. A vital component of comprehensive care for cancer patients is addressing potential threats to their reproductive health. Referral for counselling about fertility preservation options is associated with less regret and greater quality of life. Oncofertility referral pathways should be implemented in every centre providing cancer care. It is recommended that patients at risk are referred for psychological support when needed. For medical oncologists, a comprehensive overview of fertility diminishing effects that may result from the admission of specific anti-cancer drugs would be advantageous. Future research should mainly target methods to improve access to care by facilitating reliable referral pathways and decision-making processes for patients, survivors and oncology health professionals. Furthermore, existing uncertainties regarding the exact treatment risks of cancer-related infertility should be investigated. Incorporation of oncofertility education in medical school, residency and fellowship curricula should be undertaken. Furthermore, nurses, nurse practitioners and physician assistants can assist medical doctors in the process of counselling and referral for fertility preservation and should be involved in educational initiatives. Adequate patient information provision on fertility risks and fertility preservation options is identified as a critical component of oncofertility care, should be improved in quality and available in

different formats. All patients and survivors would benefit from fertility-related psychological support implemented into standard practice from diagnosis through to survivorship.



# Chapter 15

*Nederlandse samenvatting*





# INTRODUCTIE

## Kanker en seksualiteit

Geconfronteerd worden met een kankerdiagnose is een life-event, met grote gevolgen voor de kwaliteit van leven en de partnerrelatie. De behandelingen en overleving van veel vormen van kanker zijn de afgelopen jaren drastisch verbeterd, maar kunnen de endocriene, reproductieve en seksuele functie aantasten. Voor de meeste kankerpatiënten is seksuele functie een bewezen, belangrijk aspect van de kwaliteit van leven, ongeacht leeftijd en type kanker. Bij 41,2% van de patiënten met een van de tien meest voorkomende kankers is seksuele disfunctie ongeveer een jaar na de diagnose een belangrijk aandachtspunt. Seksuele bijwerkingen zijn zeer uiteenlopend en ontstaan zeker niet alleen bij de behandeling van kanker van voortplantingsorganen. Door de toename van het aantal overlevenden van kanker neemt de aandacht voor overleven van kanker navenant toe. Voor de meeste patiënten omvat het overleven van kanker het behoud van een bevredigende kwaliteit van leven, samen met het vermogen om naar tevredenheid seksueel te kunnen functioneren. Desalniettemin wordt om verschillende redenen aan seksueel functioneren vaak weinig aandacht besteed door oncologische zorgverleners. Weinig kankerpatiënten herinneren zich dat mogelijke seksuele bijwerkingen zijn besproken voordat ze met hun behandeling begonnen, en evenmin herinneren ze zich het bespreken van behandelingsopties voor seksuele problemen na de behandeling. Omgaan met seksuele problemen tijdens en na de behandeling van kanker lijkt een delicate aangelegenheid te blijven voor zorgverleners, patiënten en hun partners. Het afgelopen decennium is er behoorlijke hoeveelheid literatuur verschenen die het belang van seksueel functioneren bij kankerpatiënten benadrukt. In welke mate rekening wordt gehouden met seksuele problematiek van kankerpatiënten in de Nederlandse oncologiepraktijk is tot nu toe nog niet bekend en daarmee de aanleiding voor dit proefschrift.

## Vruchtbaarheidsstoornis als gevolg van kankerbehandeling

Behandelingen van kanker kunnen leiden tot verminderde vruchtbaarheid en invloed hebben op gezinsplanning bij patiënten van vruchtbare leeftijd (door de WHO gedefinieerd als 15-49 jaar). Niet alleen kunnen verschillende kankerbehandelingen de vruchtbaarheid beïnvloeden, in specifieke groepen zoals zaadbalkanker en lymfoompatiënten kan de vruchtbaarheid al verminderd zijn voordat de behandeling is gestart. Vrouwelijke overlevenden van kanker hebben 39% minder kans om zwanger te worden vergeleken met de algemene bevolking. Toekomstige vruchtbaarheidsperspectieven zijn iets beter bij mannelijke overlevenden, met een 26% lager zwangerschapspercentage na kanker in vergelijking met de algemene bevolking. In de afgelopen decennia is er een verscheidenheid aan snelle en effectieve methoden beschikbaar geworden om gameten, embryo's en voortplantingsweefsel te cryo preserven voor patiënten die op het punt staan een kankerbehandeling te starten. Er zijn verschillende internationale richtlijnen, netwerken en stichtingen opgesteld, die het belang onderstrepen van tijdige bespreking van

mogelijke verslechtering van de vruchtbaarheid als gevolg van kankerbehandelingen. Ondanks deze ontwikkelingen is gerapporteerd dat het praktijkgedrag en de attitudes van zorgverleners variëren, beïnvloed door verschillende barrières om dit delicate onderwerp te bespreken met kankerpatiënten van vruchtbare leeftijd. Kennis met betrekking tot fertiliteit preservatie opties en wanneer dit aangeboden dient te worden lijkt te variëren in de praktijk. Een review met betrekking tot vruchtbaarheidsproblemen bij overlevenden van kanker vermeldde counseling percentages over vruchtbaarheidsrisico's variërend van 34 tot 72%. De emotionele impact op de lange termijn van het niet kunnen verwekken van een kind is een ernstige bron van leed voor mensen die tijdens de vruchtbare leeftijd voor kanker zijn behandeld en is gecorreleerd aan verminderde kwaliteit van leven en geestelijke gezondheidsproblemen. Adequate begeleiding over mogelijk vruchtbaarheidsverlies en fertiliteit preservatie voor niet alleen de behandelende arts, maar ook door een vruchtbaarheidsspecialist, gaat gepaard met minder spijt en een hogere kwaliteit van leven voor overlevenden van kanker. Het voornemen ontstond om te onderzoeken of patiënten goed geïnformeerd worden over onvruchtbaarheidsrisico's, de opties met betrekking tot vruchtbaarheidsbehoud en of er voldoende ondersteuning wordt geboden om hen voorafgaand aan de behandeling te begeleiden bij hun reproductieve besluitvorming. Door deze kennis te bundelen vanuit het perspectief van zowel artsen, verpleegkundigen als patiënten, kunnen aanbevelingen worden opgesteld voor verbeteringen in de klinische zorg voor deze kwetsbare groep die het risico loopt hun voortplantingsvermogen te verliezen.

## **Deel I Communicatie over seksuele problematiek tussen oncologiepatiënten en zorgverleners**

### **Hoofdstuk 2**

#### ***Bespreken van veranderd seksueel functioneren met oncologiepatiënten: een cross-sectioneel onderzoek onder Nederlandse oncologieverpleegkundigen***

Bij de meeste soorten kanker kunnen de ziekte en de behandeling leiden tot een veranderde seksuele functie (SF). Oncologieverpleegkundigen zijn strategisch gesitueerd om SF bespreekbaar te maken, gezien ze frequente patiëntencontacten hebben. Ons doel was om hun kennis over en houding ten opzichte van SF in de oncologisch verpleegkundige praktijk vast te stellen en barrières voor het bespreken van het onderwerp in kaart te brengen. Een vragenlijst met 37 items werd afgenomen tijdens de V&VN Oncologiedagen 2012 en gemaild naar 241 Nederlandse verpleegafdelingen oncologie. De meerderheid van de 477 reagerend verpleegkundigen (87,6%) was het erover eens dat het bespreken van SF hun verantwoordelijkheid is. Het routinematig bespreken van SF wordt uitgevoerd door 33,4% van deze verpleegkundigen, gesprekken bestonden voornamelijk uit het noemen van bijwerkingen van de behandeling die SF kunnen beïnvloeden (71,3%). Er waren significante verschillen in de mate van bespreken wat betreft werkervaring, kennis, leeftijd, academische graad en afdelingsbeleid. Verpleegkundigen ≤44 jaar

oud ( $p < 0,001$ ), met  $< 10$  jaar oncologie-ervaring ( $p = 0,001$ ), onvoldoende kennis ( $p < 0,001$ ), geen academische graad ( $p < 0,001$ ), en op wiens afdeling geen protocol ten aanzien van het bespreken van SF was ( $p < 0,001$ ), bespraken minder vaak het SF met patiënten. Barrières waren onder meer een gebrek aan training, aanwezigheid van een derde partij en geen insteek of aanleiding om een gesprek hierover te starten. Bevindingen suggereren dat oncologieverpleegkundigen counseling over seksuele kwesties als eigen verantwoordelijkheid beschouwen, in lijn met het bespreken van andere bijwerkingen die door de ziekte of de behandeling kunnen worden veroorzaakt. Desalniettemin krijgen oncologiepatiënten mogelijk niet routinematig seksuele counseling door oncologieverpleegkundigen. De resultaten benadrukken het potentiële voordeel van educatie, inclusief praktische training en een compleet afdelingsprotocol.

### Hoofdstuk 3

#### *Management van seksuele bijwerkingen binnen de chirurgische oncologie: een landelijk onderzoek onder Nederlandse oncologisch chirurgen*

Seksueel functioneren is een belangrijke factor in de kwaliteit van leven, maar kan nadelig beïnvloed worden door verschillende chirurgisch oncologische behandelingen. Ons doel was om de praktijk, verantwoordelijkheid, attitudes, kennis en barrières van oncologisch chirurgen te identificeren wat betreft het bespreken van seksuele bijwerkingen en geven van begeleiding bij seksuele problematiek. Aan alle 437 leden van de Nederlandse Vereniging voor Chirurgische Oncologie (NVCO) is een vragenlijst met 31 items gestuurd. De meerderheid van de 165 reagerende oncologisch chirurgen (85,5%) verklaarde dat het bespreken van seksuele functie hun verantwoordelijkheid is, 13% vond het de verantwoordelijkheid van iemand anders. Tijdens informed consent gesprekken van een geplande chirurgische ingreep worden seksuele bijwerkingen in meer dan de helft van de gevallen door 36,6% van de chirurgen benoemd. Het bespreken van seksueel functioneren werd in meer dan de helft van de gevallen door 9,2% van de chirurgen uitgevoerd. Oudere chirurgen ( $\geq 46$  jaar) en mannelijke chirurgen bespreken vaker seksuele problemen ( $p = 0,006$  v  $p = 0,045$ ). De meest genoemde barrières waren hoge leeftijd van de patiënt (50,6%), niet relevant voor alle soorten kanker (43,8%), tijdgebrek (39,9%) en geen insteek of aanleiding om te vragen (35,2%). Volgens 46,3% was aanvullende training nodig om patiënten te begeleiden bij seksuele problemen. Concluderend bespreken oncologisch chirurgen niet routinematig seksuele problemen. Informed consent omvat beperkte informatie over mogelijke complicaties van het seksueel functioneren. Chirurgen beschouwen zichzelf als verantwoordelijk voor het ter sprake brengen van seksuele disfunctie, maar beschouwen hoge leeftijd van patiënten, gebrek aan tijd en geen insteek of aanleiding om te vragen als belangrijke barrières. De resultaten benadrukken de noodzaak van bewustmaking van de omvang van het probleem onder chirurgen en het geven van (praktische) training.

## Hoofdstuk 4

### *Seksuele problematiek na (bekken) radiotherapie: is er een rol voor de radiotherapeut?*

Seksueel functioneren is een belangrijk aspect van kwaliteit van leven en kan verminderd zijn na (bekken) bestraling. Het doel van deze studie was om de praktijk, verantwoordelijkheid, kennis en barrières van Nederlandse radiotherapeuten met betrekking tot seksuele begeleiding in kaart te brengen. Er werd een cross-sectioneel onderzoek uitgevoerd met een vragenlijst van 28 items die naar alle leden van de Nederlandse Vereniging voor Radiotherapie en Oncologie werd gestuurd. Van de ondervraagde steekproef voltooide 54,6% van de stralingsoncologen de vragenlijst (n = 119). De frequentie van het bespreken van seksuele functie was wisselend, afhankelijk van het type tumor. De meerderheid van de radiotherapeuten (75%) was het ermee eens dat het bespreken van seksuele functie hun verantwoordelijkheid is, ongeveer een derde (33,6%) wees op de betrokken specialist (chirurg, uroloog, gynaecoloog of oncoloog), een vijfde beschouwde ook huisarts verantwoordelijk (21%). Aanvullende training over het bespreken van seksualiteit was volgens 44,4% vereist, de meerderheid was het ermee eens dat seksuele counseling een vast onderdeel zou moeten zijn van de opleiding tot radiotherapeut (n = 110, 94%). De meest genoemde barrières waren: patiënt is te ziek (36,2%), geen insteek of aanleiding om te vragen (32,4%), gevorderde leeftijd van de patiënt (27%) en cultuur / religie (26,1%). Voor prostaatkankerpatiënten werd informatie over fosfodiësterase 5-remmers regelmatig (49,2%) en vaak (40,7%) verstrekt. Radiotherapeuten voeren over het algemeen seksuele counseling uit in het geval van bekkenbestraling, maar niet consistent in het geval van gastro-intestinale, borst- en andere vormen van kanker. Het merendeel van de radiotherapeut-oncologen beschouwde counseling over seksueel functioneren als een onderdeel van hun werk, sommigen wezen ook op de verwijzer of huisarts. De bevindingen suggereren dat radiotherapeuten zich bewust zijn van seksuele disfunctie, maar dat de verantwoordelijkheid voor actieve counseling onzeker is. De resultaten benadrukken de noodzaak om educatieve en praktische training te bieden, evenals een systeem voor gespecialiseerde verwijzingen.

## Hoofdstuk 5

### *Seksuele gezondheid in de praktijk van de medisch-oncoloog: onderzoek naar de huidige praktijk en uitdagingen*

Seksualiteit is voor veel kankerpatiënten een belangrijke onderdeel van de kwaliteit van leven. Patiënten kunnen worden benadeeld als ze niet worden geïnformeerd en geen seksuele counseling krijgen aangeboden. We probeerden de huidige praktijk en meningen van oncologen over het counsellen van seksuele problematiek te in kaart te brengen. Het doel van deze studie was om de kennis, attitude en dagelijkse praktijk van medisch oncologen in Nederland met betrekking tot aan behandeling gerelateerde seksuele disfunctie te onderzoeken. Er zijn vra-

genlijsten gestuurd naar 433 leden van de Nederlandse Vereniging voor Medische Oncologie. De meerderheid (81,5%) van de 120 medische oncologen die reageerden (respons 30,6%) verklaarde dat ze seksueel functioneren bespraken met minder dan de helft van hun patiënten. Tegelijkertijd was 75,8% van de deelnemende oncologen het erover eens dat het aanpakken van seksuele functie wel hun verantwoordelijkheid is. Seksuele functie werd vaker besproken met jongere patiënten en patiënten met een curatieve behandelintentie. Barrières om het bespreken van seksuele functie te vermijden waren tijdgebrek (56,1%), training (49,5%) en gevorderde leeftijd van de patiënt (50,4%). Meer dan de helft (64,6%) gaf aan weinig kennis over het onderwerp te hebben en de meerderheid (72,9%) wilde bijscholing in het begeleiden van problemen met seksueel functioneren. Medische oncologen aanvaarden dat counseling op het gebied van seksuele functie binnen hun beroep valt, maar geven toe dat ze patiënten niet routinematig bevragen met betrekking tot seksueel functioneren. Slechts in een minderheid van de gevallen informeren oncologen hun patiënten over seksuele bijwerkingen van de behandeling. Of ze patiënten adviseren, hangt samen met de leeftijd van de patiënt en hoe ze de prognose van de patiënt en kennis op het gebied van seksueel functioneren inschatten. Uit de bevindingen blijkt dat er behoefte bestaat voor het aanbieden van onderwijs en praktijktraining.

## Hoofdstuk 6

### *Tekortkomingen in de opleiding tot uroloog met betrekking tot seksuele disfunctie na de behandeling van prostaatkanker: het identificeren van een behoefte*

Het doel was om de huidige kennis, praktijk, eerdere training, barrières en trainingsbehoeften van urologen in opleiding in kaart te brengen met betrekking tot prostaatkanker gerelateerde seksuele disfunctie. In een cross-sectionele vragenlijststudie werd de praktijkvoering en de trainingsbehoefte van urologen in opleiding geïnventariseerd die in juni 2015 een landelijke training volgden. Van de 101 urologen in opleiding door heel Nederland volgden er 87 de training (respons 100%). De mediane leeftijd was 32 jaar (spreiding 28-38); 55,2% was een vrouw. Ongeacht het opleidingsjaar hadden de meeste artsen nooit voorlichting over seksuele disfunctie genoten (58,6%), rapporteerden zij een beperkt kennisniveau (48,3%) en gaven zij aan dat ze behoefte hadden aan training (69,4%). De meerderheid voelde zich niet competent om prostaatkankerpatiënten te adviseren over de behandeling van seksuele disfunctie (55,2%). Bijna alle deelnemers vroegen naar preoperatieve erectiestoornissen (89,7%) en waren op de hoogte van potentiële behandeling gerelateerde seksuele disfunctie (88,5%). Bij de follow-up vroeg 63,9% van de artsen opnieuw naar seksuele klachten. Meer dan de helft van de deelnemers gaf aan dat de opleiding tot uroloog onvoldoende educatie biedt over seksuele disfunctie (54,8%). Tijdsdruk (67,1%) en gebrek aan scholing (35,3%) waren de meest genoemde barrières. De huidige opleiding tot uroloog besteedt onvoldoende aandacht aan seksuele communicatieve vaardigheden en seksuele disfunctie. De urologen in opleiding hebben behoefte

aan meer kennis over en meer praktische training in seksuele begeleiding. Bevindingen ondersteunen inspanningen om de opleiding tot uroloog te verbeteren wat betreft de behandeling van prostaatkanker gerelateerde seksuele disfunctie.

## Hoofdstuk 7

### ***Seksualiteit bespreken op het gebied van plastische en reconstructieve chirurgie: een landelijke studie naar de huidige praktijk in Nederland***

Door de patiënt gerapporteerde uitkomsten zijn steeds belangrijker geworden om de waarde van chirurgische ingrepen te beoordelen. Seksueel functioneren is een bewezen belangrijk onderdeel van kwaliteit van leven, maar wordt vaak over het hoofd gezien door beroepsbeoefenaren in de gezondheidszorg. We willen onderzoeken in hoeverre plastisch chirurgen seksualiteitskwesties met hun patiënten aanpakken of bespreken, en of er behoefte is aan verbetering. We ontwikkelden een enquête om te beoordelen of onderwerpen met betrekking tot seksueel functioneren aan de orde komen tijdens plastische chirurgische consulten. In 2016 zijn alle 385 leden van de Nederlandse Vereniging voor Plastische Chirurgie via de post uitgenodigd om deel te nemen. We hebben 106 ingevulde enquêtes ontvangen (27,5%). De mediane leeftijd van de respondenten was 45 (29-66) jaar. De meeste deelnemers (78,3%) gaven aan zelden seksualiteit met hun patiënten te bespreken. Chirurgen in de subspecialisatie gender- en genitale chirurgie bespraken het seksueel functioneren het vaakst. Twee derde van alle respondenten gaf aan dat hun huidige kennis over dit onderwerp onvoldoende was, maar over het algemeen bestond er geen interesse in het volgen van aanvullende training (78,6%). Er was wel behoefte aan goede patiënten brochures (43,4%) en een georganiseerd verwijzingsnetwerk (36,5%) over seksualiteit. In de praktijk van de plastische chirurgie blijkt seksualiteit een zelden besproken onderwerp te zijn, met uitzondering van de sub specialismen gender- en genitale chirurgie. Hoewel professionals en patiënten het belang van seksualiteit benadrukken, uiten plastisch chirurgen een beperkte behoefte om geschoold te worden, geven ze de voorkeur aan schriftelijke patiëntinformatie en verwijzen patiënten door naar andere zorgprofessionals. De auteurs stimuleren meer educatie over seksualiteit tijdens (vervolg)opleidingen plastische chirurgie.

## Hoofdstuk 8

### ***Schriftelijk voorlichtingsmateriaal en beschikbaarheid van seksuele gezondheidszorg voor mannen met seksuele disfunctie na de behandeling van prostaatkanker: een evaluatie van de Nederlandse afdelingen urologie en radiotherapie***

Het doel was om de inhoud van schriftelijk voorlichtingsmateriaal en de beschikbaarheid van seksuele gezondheidszorg voor mannen met seksuele disfunctie (SD) na behandeling van prostaatkanker te onderzoeken. Er is een cross-sectioneel onderzoek uitgevoerd onder de Ned-

erlandse afdelingen urologie en radiotherapie om voorlichtingsmateriaal en de beschikbaarheid van seksuele gezondheidszorg te evalueren. Van de 71 in aanmerking komende afdelingen namen 34 afdelingen urologie en 15 afdelingen radiotherapie deel aan het onderzoek (respons 69,0%). Negenenvijftig brochures die overeenkomen met 31 afdelingen urologie en 11 radiotherapie werden geanalyseerd. In 88,1% van het verzamelde informatiemateriaal werd seksuele gezondheid genoemd. Wat betreft uitgebreidheid: 20,4% van de brochures bevatte uitgebreide informatie, 50,8% matige hoeveelheid informatie en 28,8% bevatte weinig of geen informatie. Op de afdelingen urologie was er vaker verpleegkundig consult voorafgaand aan de behandeling dan op afdelingen radiotherapie. Seksuele counseling werd vaker aangeboden door urologie afdelingen. Urologie afdelingen waren beter op de hoogte van verwijzingsmogelijkheden. Voorlichtingsmateriaal van de Nederlandse urologie- en radiotherapie-afdelingen gaat niet routinematig in op behandeling gerelateerde SD. Seksuele gezondheidszorg is niet overal beschikbaar voor mannen met SD. Het wordt aanbevolen een norm toe te passen met betrekking tot de inhoud van voorlichtingsmateriaal wat betreft seksueel functioneren, evenals een betere beschikbaarheid van verwijzingsmogelijkheden en het aanbieden van verpleegkundige consulten vooraf aan de behandeling van mannen met prostaatkanker.

## **Deel II Bespreking van vruchtbaarheidsproblematiek met oncologiepatiënten**

### **Hoofdstuk 9**

#### ***Counseling voor behoud van vruchtbaarheid in de Nederlandse oncologiepraktijk: zijn verpleegkundigen klaar om artsen bij te staan?***

Kanker en de behandeling ervan kunnen resulteren in verminderde vruchtbaarheid, wat langdurig leed kan veroorzaken bij overlevenden van kanker. Voor in aanmerking komende patiënten is fertiliteit preservatie (FP) beschikbaar om de kans op toekomstig nageslacht veilig te stellen. Veel artsen voelen zich echter geremd bij het bespreken van FP. Oncologieverpleegkundigen kunnen als initiator optreden bij de bespreking van het onderwerp en aanvullende ondersteuning bieden. Ons doel was om hun kennis over FP, de manier waarop ze dit toepassen, en mogelijke barrières voor het bespreken van FP met patiënten in de vruchtbare leeftijd te onderzoeken. Een vragenlijst werd afgenomen via mail, internet en de V&VN Oncologiedagen. Vierhonderd eenentwintig oncologieverpleegkundigen namen deel, van wie een derde (31,1%) “voldoende” kennis van FP had. Achtentwintig procent van de deelnemers meldde dat ze “nooit / bijna nooit” FP bespraken; 32,2% “bijna altijd / altijd.” FP-discussies werden vaker gevoerd door verpleegkundigen met een master opleiding, academisch werkende verpleegkundigen, ervaren verpleegkundigen en verpleegkundigen met voldoende kennis. Redenen om FP niet te bespreken waren “gebrek aan kennis” (25,2%), “slechte prognose” (16,4%) en “gebrek aan tijd” (10,5%). Concluderend kunnen verschillende obstakels ertoe leiden dat FP niet routinematig



wordt besproken, met name een gebrek aan kennis. Toch voelen verpleegkundigen zich verantwoordelijk voor het aanpakken van het probleem, wat aangeeft dat hulp bij FP-discussies moet worden aangemoedigd. Educatieve training over FP wordt aanbevolen.

## Hoofdstuk 10

### ***Een educatieve behoefte met betrekking tot behandeling gerelateerde onvruchtbaarheid en fertiliteitspreservatie; een landelijke enquête onder leden van de Nederlandse Vereniging voor Medische Oncologie***

De diagnose en de behandeling van kanker kunnen de reproductieve planning en vruchtbaarheid beïnvloeden bij patiënten van vruchtbare leeftijd. Hoewel er in het afgelopen decennium richtlijnen zijn opgesteld, blijven opleiding, praktijk en de houding van medisch oncologen met betrekking tot fertiliteitspreservatie onbekend. Er is een landelijke enquête gehouden onder leden van de Nederlandse Vereniging voor Medische Oncologie. Demografische gegevens, praktijkvoering, kennis en barrières werden gemeten wat betreft informatievoorziening over fertiliteitspreservatie aan kankerpatiënten van vruchtbare leeftijd. Van 392 leden hebben 120 oncologen de vragenlijst ingevuld (30,6%). De meerderheid van de oncologen was ervan overtuigd dat het hun verantwoordelijkheid is om de impact van kankerbehandeling op de vruchtbaarheid te bespreken (93,2%), maar 68,3% besprak het onderwerp vaak of altijd (n=82). Oncologen werkzaam in perifere ziekenhuizen waren minder geneigd om over vruchtbaarheid te praten (p=0,033). Gemiddeld wordt 44,6% van de reproductieve mannen en 28,9% van de reproductieve vrouwen doorverwezen naar fertiliteitsartsen. De helft van de respondenten gaf aan voldoende kennis te hebben over fertiliteitspreservatie (n=57, 47,5%). Een slechte prognose (53%), onwaarschijnlijke overleving (43,1%) en hoge kans op vruchtbaarheidsherstel (28,7%) werden genoemd als barrières voor het bespreken van fertiliteitspreservatie. Onder medisch oncologen is de impact van kankerbehandeling op vruchtbaarheid een algemeen aanvaarde verantwoordelijkheid om te bespreken. Desondanks varieert de door hen zelf gescoorde kennis over fertiliteitspreservatie sterk. In de praktijk wordt vruchtbaarheid tot op zekere hoogte besproken, beïnvloed door verschillende barrières en afhankelijk van de prognose en het type ziekenhuis. Patiënten hebben baat bij kennisverbetering onder oncologische zorgverleners over fertiliteitseffecten van kankerbehandeling. Onderwijs tijdens de geneeskunde studie, specialisatie en onder praktiserend oncologen kan het bewustzijn vergroten. Er is ruimte voor verbetering van de verwijzingsmogelijkheden.

## Hoofdstuk 11

### ***Identificatie van de noodzaak om vruchtbaarheidsproblemen te bespreken bij patiënten met zaadbalkanker; een evaluatie (INDICATE studie)***

Mannen met testiscarcinoom (TC) riskeren verminderde vruchtbaarheid. Vruchtbaarheid is een belangrijk aandachtspunt voor TC patiënten, gezien de diagnose bijna altijd wordt gesteld bij patiënten van reproductieve leeftijden en gezien de hoge algehele overleving. In deze studie werd counseling nagevraagd met betrekking tot het risico op verminderde vruchtbaarheid en cryopreservatie van sperma. Een cross-sectioneel onderzoek werd uitgevoerd bij 566 TC patiënten die tussen 1995-2015 werden gediagnosticeerd. Van de 566 overlevenden zijn 201 vragenlijsten ingevuld (35,5%). Achtentachtig procent werd geïnformeerd over mogelijk verminderde vruchtbaarheid, 9,5% werd niet geïnformeerd. De meerderheid (47,3%) gaf de voorkeur aan de uroloog om informatie te verstrekken. Het inleveren van sperma was lastig maar succesvol voor 25,6%, 4,8% slaagde er niet in om sperma in te leveren. De redenen waren hoge druk door ziekte, pijn na operatie en een ongemakkelijke setting. Vanwege verminderde vruchtbaarheid meldde 19% van de respondenten verdriet en 9,3% gaf aan minder tevreden te zijn in het leven. Het invriezen van sperma werd uitgevoerd met 41,3% (n = 83). Een derde (n = 63, 31,3%) kreeg kinderen na behandeling, waarvan 11,1% gebruik maakte van geconserveerd sperma (n = 7). De resultaten van dit onderzoek geven het belang aan van het tijdig bespreken van vruchtbaarheidsproblematiek met TC patiënten. Hoewel het met de meeste mannen wordt besproken, kunnen ontevredenheid en verdriet optreden als gevolg van verminderde vruchtbaarheid en een gebrek aan begeleiding daarin. In totaal maakte 6,5% gebruik van gecryopreserveerd sperma (n = 13). Mannen geven er de voorkeur aan dat hun uroloog advies geeft over vruchtbaarheid.

## Hoofdstuk 12

### ***Seksuele en vruchtbaarheid gerelateerde bijwerkingen van medicamenteuze kankerbehandeling; een landelijke evaluatie onder medisch oncologen***

Geneesmiddelen tegen kanker hebben vaak een negatieve invloed op de vruchtbaarheid en seksuele functie, desondanks melden patiënten dat ze niet worden geadviseerd over deze mogelijke bijwerkingen. Het doel was om de kennis van Nederlandse oncologen vast te stellen over de bijwerkingen van verschillende kankermedicijnen op de vruchtbaarheid en seksuele functie. Er is een cross-sectioneel onderzoek gedaan onder leden van de Nederlandse Vereniging voor Medische Oncologie (n=433). De enquête vroeg naar nadelige effecten op de vruchtbaarheid, ovulatie, spermatogenese en seksuele functie van verschillende kankermedicijnen. Honderdvijf van 392 oncologen reageerden (26,8%). Oncologen waren zich meer bewust van nadelige effecten op de vruchtbaarheid in vergelijking met effecten op de seksuele functie. Geneesmiddelen waarvan het meest werd aangenomen dat ze de vruchtbaarheid negatief beïnvloeden, waren

cisplatine (n=81, 80,2%), epirubicine (n=78, 78,0%) en cyclofosfamide (n=80, 77,7%). Wat betreft seksuele functie waren de meest genoemde geneesmiddelen tamoxifen (n=67, 65,7%), GnRH-agonisten (n=64, 63,4%) en cisplatine (n=58, 57,4%). Oncologen met expertise op het gebied van urologie waren zich meer bewust van seksualiteit gerelateerde bijwerkingen (cisplatine p=0.038, etoposide p=0.025, ifosfamide p=0.06, vinblastine p=0.000). Er is ruimte voor verbetering als het gaat om de kennis van oncologen over mogelijke vruchtbaarheids- en seksualiteitsbijwerkingen van kankermedicijnen. Op basis van onze resultaten beschikken oncologen niet over voldoende kennis om patiënten adequaat te informeren over deze bijwerkingen en indien nodig advies te geven of door te verwijzen voor begeleidende counseling.

## DISCUSSIE EN TOEKOMSTPERSPECTIEVEN

Met de in dit proefschrift gepresenteerde studies hebben we getracht een stap voorwaarts te zetten in het in kaart brengen van de huidige praktijk en barrières bij het bespreken van het seksueel functioneren en vruchtbaarheid in de medische en chirurgische oncologie in Nederland.

### Deel I Communicatie over seksuele problematiek tussen oncologiepatiënten en zorgverleners

Het eerste deel van dit proefschrift toonde de bestaande belemmeringen aan bij de ondervraagde respondenten bij het bespreken van seksuele bijwerkingen en functioneren tijdens de dagelijkse praktijk. In het algemeen bestaat er onder oncologische zorgverleners in Nederland consensus over de verantwoordelijkheid voor het aanpakken van (mogelijke) seksuele disfunctie voor en na de behandeling. Ondanks dit verantwoordelijkheidsbesef, wordt het bespreken van het seksueel functioneren als zorgstandaard niet structureel uitgevoerd. De kennis over het aangaan van een gesprek over het seksueel functioneren, het behandelen van seksuele functiestoornissen en mogelijke bijwerkingen van anti-kankermedicijnen is beperkt, en een behoefte aan scholing wordt door een aanzienlijk aantal verpleegkundigen en artsen geuit. Verder lijken verwijzingsmogelijkheden, patiëntenvoorlichtingsmateriaal en afdelingsprotocollen te ontbreken; updates zouden zowel patiënten als medische professionals in de dagelijkse praktijk ten goede kunnen komen. Beoordelingen van de seksuele functie worden niet regelmatig uitgevoerd door zorgverleners in de klinische oncologische setting. De meest genoemde barrières onder Nederlandse oncologische zorgverleners waren gebrek aan training en gebrek aan tijd, geen insteek of aanleiding om een gesprek te beginnen, gevorderde leeftijd van patiënten, aanwezigheid van een derde en te zieke patiënten. Het is aan te bevelen dat elke oncologische afdeling seksuele functie als item opneemt in haar protocollen. Het geven van scholing zal worden gewaardeerd en het bewustzijn vergroten. Standaardisatie van het geven van informed consent met vermelding van bijwerkingen van operaties, bestraling en anti-kankermedicijnen, kan bijdragen aan een betere informatievoorziening en bijdragen aan het verwachtingenmanagement van patiënten.

Korte counseling zou kunnen worden gegeven door één gespecialiseerde zorgverlener in een oncologisch behandelteam, bijvoorbeeld een verpleegkundig specialist. Een minderheid van de patiënten zal een gespecialiseerde, intensieve medische of psychologische behandeling nodig hebben voor seksuele problemen. Een algemeen beschikbaar overzicht van seksuele bijwerkingen die het gevolg kunnen zijn van anti-kankermedicijnen zou nuttig zijn. Toekomstig onderzoek zou zich moeten richten op studies naar het effect van verschillende varianten van educatieve training voor oncologische zorgverleners. Empirisch onderzoek moet zich richten op hoe om te gaan met informatieverstrekking, counseling en follow-up voor seksuele functiestoornissen bij kankerpatiënten. Een nadere beschouwing van de specifieke behoeften van bepaalde soorten kanker wordt aanbevolen. Geschikte begeleiding voor partners moet ook worden geëvalueerd. Met name moet worden onderzocht welke coping strategieën effectief zijn voor seksuele zorgen tijdens en na kanker, zowel voor alleenstaande patiënten als voor paren van alle leeftijden.

## **Deel II Bespreking van vruchtbaarheidsproblematiek met oncologiepatiënten**

Deel twee van dit proefschrift beschrijft zelf gerapporteerde praktijkroutines met betrekking tot de counseling over verminderde vruchtbaarheid en de mogelijkheid van vruchtbaarheidsbehoud bij patiënten in de reproductieve leeftijd die te maken krijgen met kanker. Voor zaadbalkankerpatiënten hebben we specifieke items gerapporteerd over de bespreking, verwijzing voor en het proces van semen cryopreservatie. Bij deze overlevenden van zaadbalkanker werden zorgen over de voortplanting op lange termijn vastgesteld. Zowel medisch oncologen als oncologieverpleegkundigen meldden dat de impact van de kankerbehandeling op de vruchtbaarheid werd besproken. Dit gebeurde echter niet in alle gevallen en was afhankelijk van verschillende factoren zoals opleidingsniveau, werkervaring, type ziekenhuis, prognose van de patiënt en kansen op herstel van de vruchtbaarheid. De belangrijkste redenen voor medisch oncologen om vruchtbaarheidskwesties niet te bespreken, waren een slechte prognose, onwaarschijnlijke overleving van de behandeling en een hoge kans op herstel van de vruchtbaarheid na de behandeling. Voor verpleegkundigen waren deze redenen een gebrek aan kennis, een slechte prognose en een gebrek aan tijd tijdens de consulten. De INDICATE-gegevens toonden aan dat reproductieve zorgen op lange termijn, verdriet en minder tevredenheid in het leven voorkwamen bij mannen die teelbalkanker hadden overleefd. Meetinstrumenten voor reproductieve zorgen kunnen helpen bij het screenen op zorgen bij overlevenden van kanker in de reproductieve leeftijd en leiden tot een tijdige doorverwijzing voor psychosociale ondersteuning. Een vitaal onderdeel van zorg voor kankerpatiënten is het aanpakken van potentiële risico's voor hun reproductieve gezondheid. Verwijzing voor counseling over opties voor vruchtbaarheidsbehoud wordt in verband gebracht met minder spijt en een hogere kwaliteit van leven. In elk centrum voor kankerzorg zouden verwijzingsroutes voor oncofertiliteit moeten worden bewerkstelligd. Aanbevolen wordt risicopatiënten zo nodig door te verwijzen voor psychologische ondersteuning. Voor medisch oncologen zou een uitgebreid overzicht van vruchtbaarheid verminderende

effecten die kunnen voortvloeien uit geneesmiddelen tegen kanker nuttig zijn. Toekomstig onderzoek moet vooral gericht zijn op methoden om de toegang tot zorg te verbeteren door betrouwbare doorverwijzingstrajecten en door besluitvorming voor patiënten, overlevenden en oncologische zorgverleners te vergemakkelijken. Verder moeten de bestaande onzekerheden over de precieze behandelingsrisico's van aan kanker gerelateerde onvruchtbaarheid worden onderzocht. Integratie van oncofertiliteitsonderwijs in de curricula van de medische faculteit, de specialisten opleiding en fellowships moet worden ondernomen. Bovendien kunnen verpleegkundigen, nurse practitioners en physician assistants artsen bijstaan in het proces van counseling en verwijzing voor vruchtbaarheidsbehoud en dienen zij betrokken te worden bij educatieve initiatieven. Adequate patiëntenvoorlichting over vruchtbaarheidsrisico's en opties voor vruchtbaarheidsbehoud wordt beschouwd als een cruciaal onderdeel van oncofertiliteitszorg, moet kwalitatief worden verbeterd en in verschillende formaten beschikbaar worden gesteld. Patiënten en overlevenden zouden baat hebben bij psychologische ondersteuning gerelateerd aan vruchtbaarheidsproblematiek die vanaf diagnose tot en met follow-up in de standaardpraktijk wordt opgenomen.





# PART IV

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## Appendices

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## LIST OF ABBREVIATIONS

ADT	Androgen deprivation therapy
ASCO	American Society of Clinical Oncology
AYA	Adolescents and young adults
BT	Brachytherapy
CIS	Carcinoma in situ
EBRT	External beam radiotherapy
ED	Erectile dysfunction
FP	Fertility preservation
IKNL	Integraal Kankercentrum Nederland (Comprehensive Cancer Center of the Netherlands)
IQR	Interquartile range
LUMC	Leiden University Medical Center
NA	Not available/Not applicable
NFK	Nederlandse Federatie van Kankerpatiënten (Dutch Federation of Cancer patients)
NVCO	Nederlandse Vereniging voor Chirurgische Oncologie (Dutch Society for Surgical Oncology)
NVMO	Nederlandse Vereniging voor Medische Oncologie (Dutch Society of Medical Oncology)
NVPC	Nederlandse Vereniging voor Plastische Chirurgie (Dutch Society of Plastic Surgery)
NVRO	Nederlandse Vereniging voor Radiotherapie en Oncologie (Dutch Association for Radiotherapy and Oncology)
NS	Not significant
PDE5	Phosphodiesterase type 5 inhibitor
PESA	Percutaneous epididymal sperm aspiration
PLISSIT	Permission (P), limited information (LI), specific suggestion (SS) and intensive therapy (IT)
PRO	Patient-reported outcome
PSA	Prostate-specific antigen
RCS	Reproductive Concern Scale
RPLND	Retroperitoneal lymph-node dissection
RT	Radiotherapy
SABS	Sexuality Attitudes and Beliefs Survey
SAM	Suitability Assessment of Materials
SD	Sexual dysfunction
SE	Standard error
SF	Sexual function

SmPC	Summary of Product Characteristics
TC	Testicular cancer
TESE	Testicular sperm extraction
WHO	World Health Organization

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Author Reply to Editorial Comment

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\*contributed equally

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E.M. Krouwel\*, Z. Kramer\*, R. Gordijn, M.P.J. Nicolai, S. Osanto, H. Putter, R.C.M. Pelger, H.W. Elzevier

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Supportive Care in Cancer, January 2022





## CURRICULUM VITAE

Esmée Margarete Krouwel was born in Hoevelaken on the 22nd of December 1987. After graduating from the Nassau Veluwe College Harderwijk in 2006, she pursued her passion for the medical sciences and enrolled in the Medicine Faculty at the University of Leiden in 2007. During her studies Esmée worked to obtain preliminary clinical experience; starting as a student assistant in the Cardiology department; as well as a surgical assistant at the Department of Surgery and Orthopaedics of the Diaconessenhuis Leiden. In order to obtain an international view on her profession she performed a tropical internship in Khartoum and the inland of Sudan in 2009. A scientific internship was performed at the department of Paediatric Haematology of the AMC hospital in 2011. Organizational experience was obtained by accommodating several activities, such as the Dies Symposium of the Leiden Medical Faculty of Students in 2011 and several committees of her student association LSV Minerva. During a scientific internship at the Department of Urology of the Leiden University Medical Center (LUMC) in 2012, the foundation for this thesis was built. Subsequently, she commenced her clinical rotations in the Netherlands and Paramaribo, Suriname.

After obtaining her medical degree in 2014 she started to work as a PhD student at the Department of Urology at the LUMC, supervised by promotor prof. dr. R.C.M. Pelger and co-supervisors dr. H.W. Elzevier and dr. M.P.J. Nicolai. In 2015 she started as a house officer at the Urology Department of the Haaglanden Medical Center in The Hague (supervision by drs. C.P.A.M. Berger) during which she continued writing this thesis. Her research on the counselling of sexual dysfunction and fertility concerns among oncology patients was presented at various conferences and resulted in this thesis. At the time of 2017, she commenced her residency training in the surgical department of the Haaglanden Medical Center, under the supervision of dr. H.J. Smeets. The continuation of her urology training takes place at the LUMC, Haga hospital and Antoni van Leeuwenhoek under the supervision of dr. H.W. Elzevier, dr. H. Roshani and dr. B.W.G. van Rhijn. Esmée lives together with Maurizio Moojen, they have a son Thibeau (2018) and daughter Mabel (2021).



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