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

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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 ≤ 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 (≥ 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.