Cancer and sexual health: The continuum of care

Albers, L.F.

Citation

Albers, L. F. (2021, April 7). *Cancer and sexual health: The continuum of care*. Retrieved from https://hdl.handle.net/1887/3151775

Author: Albers, L.F.
Title: Cancer and sexual health: The continuum of care
Issue date: 2021-04-07

Cancer and sexual health: the continuum of care

Leonore Frederique Albers

Cancer and sexual health: the continuum of care

Leonore Frederique Albers

Colophon

The studies in this thesis have been performed at:

- The departments of Urology, Oncology, Surgery and Medical Statistics, Leiden University Medical Center, Leiden, the Netherlands
- The department of Surgery, Groene Hart Ziekenhuis, Gouda, The Netherlands
- The department of Surgery, Haaglanden Medical Center, The Hague, The Netherlands
- The department of Urology, The Netherlands Cancer Institute – Antoni van Leeuwenhoek, Amsterdam, The Netherlands
- The Dutch Federation of Cancer Patient Organizations (NFK), Utrecht, The Netherlands
- Dutch AYA "Young and Cancer" Platform, Utrecht, The Netherlands

Additional financial support was provided by:

Coloplast BV, ChipSoft B.V., Kyowa Kirin Pharma BV

Layout: Leonore Albers
Printed by: Ipskamp Printing
ISBN: 9789464212402

Cancer and sexual health: the continuum of care

Proefschrift
ter verkrijging van
de graad Doctor aan de Universiteit Leiden
op gezag van Rector Magnificus prof.dr.ir. H. Bijl,
volgens besluit van het College voor Promoties
te verdedigen op woensdag 7 april 2021
klokke 16:15

door

Leonore Frederique Albers
geboren te Capelle aan den IJssel in 1992

Promotor: Prof. dr. R.C.M. Pelger

Co-promotor: Dr. H.W. Elzevier

Promotiecommissie: Prof. dr. H. Putter

Prof. dr. N.R. Biermasz

Prof. dr. L. Incrocci, Erasmus Medisch Centrum

Dr. Y. Reisman, Flare Health, Amstelveen

TABLE OF CONTENTS

PART I: THE PATIENT

PART II: THE PATIENT AND THEIR PARTNER

PART III: THE PATIENT AND THEIR HEALTHCARE PROFESSIONALS

PART IV: THE ORGANIZATION

PART V: FUTURE DIRECTIONS

PART VI: APPENDICES

Chapter 1: General introduction

"There is a need for reduction of impact on sexual life of medical and surgical conditions or treatments." – World Health Organization(1).

In his hierarchy of needs consisting of five stages **(Figure 1)**, the American psychologist Maslow classified sex under the physiological needs, indicating the most basic needs that have to be met by humans(2). Although the place of sex in the hierarchy of needs has been criticized, sexual health is known to be a fundamental part of life. Sexual health is a multidimensional concept with a lack of consensus in literature regarding the definition. For the purpose of this thesis, sexual health is composed of sexual self-concept, sexual functioning, sexual relationships and intimacy(3-5). The World Health Organization (WHO) defined sexual health 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(6)."

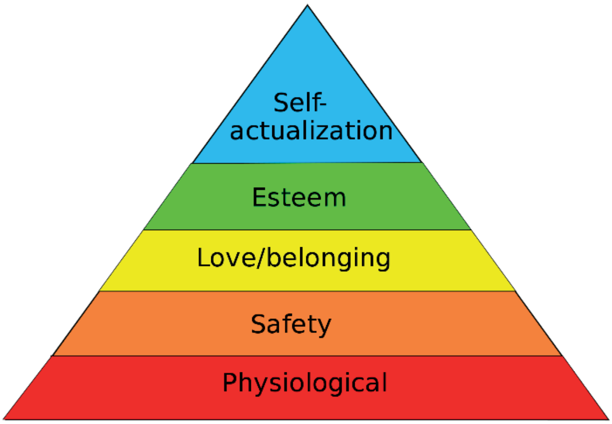


Figure 1: Maslow's hierarchy of needs
Source: Maslow, A.H, A theory of human motivation. Psychological Review 1943. 50 (4): 370–96.

Cancer and sexual health

Advances in cancer diagnosis and treatment have led to rising survival rates. As a consequence, more people are living with and beyond cancer(7-9). There is expanding recognition of problems following cancer treatment and growing attention for improving patients' wellbeing and quality of life. Sexual health is considered as an important quality of life issue(10, 11). Sexual concerns are common consequences of cancer treatment. The prevalence rates of side effects affecting sexuality varies between cancer site and treatment, up to 100%. More than half of patients treated for malignancies in the pelvic and over twenty-five percent of people with other malignancies are affected(12). The diagnosis itself and treatment can affect different domains of sexuality, both physical and psychological. Issues with sexual health may start at the beginning of treatment and are likely to continue during the follow-up and survivorship. Consequently, it can be a persistent reminder of malignancy, often far beyond end of treatment(12). As a result, cancer patients and survivors with sexual health concerns are more likely to have distress and a poorer quality of life(13, 14). Sexual problems can affect patients regardless of age, cancer site, gender or treatment.

Age

In particular, younger cancer patients experience more distress with sexual functioning in comparison to older patients(15-17). However, sexuality remains important during life, even for geriatric cancer survivors(12). A study on the prevalence of sexual activity among 10,000 European adults showed that sexual desire and activity persist through old age. Half the male participants and a quarter of the female participants between 70 and 80 years old reported to be sexually active(18). Nevertheless, sexual problems following cancer treatment of older and younger patients may differ. In case cancer occurs during adolescence or young adulthood (AYA), cancer can interfere with normal sexual development, psychosexual formation and the evolvement of romantic relationships(16, 17, 19-21).

Cancer site

Research focussed mainly on sexual concerns in 'sexual/reproductive cancers'; prostate and testicular cancer in men and gynaecological and breast cancer in women(10). However, sexual problems are not only a concern in those with a reproductive cancer, but irrespective of cancer site(10, 22-24). Other cancer site and their treatment, like hematologic, colorectal or head and neck cancer, may also cause sexual side effects(25-27).

Treatment modalities

Both men and women may suffer from sexual health problems due to cancer treatment(10, 22). Most sexual problems are not caused by the cancer itself, but by the toxicity of treatment. Damage to nerves, blood vessels and organs may cause sexual problems. All treatment modalities, as surgery, chemotherapy, hormonal therapy or radiotherapy, cause specific physical or psychological sexual problems(22). The most common sexual problems in men are erectile dysfunction and loss of sexual desire. Surgery or radiation therapy to the pelvic organs are well-known to cause erectile dysfunction due to damage to pelvic nerves and blood vessels. Besides, intensive chemotherapy or hormonal therapy may lead to hypogonadism causing sexual dysfunction(23). In women, the most common sexual problems are loss of desire, pain during intercourse and vaginal dryness.

Chemotherapy and hormonal therapy can cause (permanent) ovarian failure. Hormonal therapy and pelvic radiotherapy lead to dryness and pain during sexual intercourse. Surgery, for example a mastectomy, may cause change in nipple sensation, body image and self-esteem. Bone marrow transplantation causes scarring of the vulva and the vagina(10, 12, 28). Moreover, in both men and women, general side effects of treatment like fatigue, nausea, urinary and bowel incontinence cause problems with sexuality(12).

The partner

Most intimate partners of patients with cancer report a negative impact of the disease on their sexuality and intimacy(24, 29-33). Physical changes, adverse effects of the treatment and repositioning of their partner as asexual contribute to changes in sexual relationship between the person with cancer and the partner(24, 30, 34). Partners report to experience feelings of frustration and sadness due to these changes(34, 35). An intimate relationship during cancer treatment and survivorship is important since it is associated with better psychosocial outcomes in both cancer patients and partners(36, 37).

Discussing sexual health in medical practice

Sexual health is rated as an important unmet need during cancer survivorship(10, 12). Patient reported outcomes show poor satisfaction with support for cancer-related sexual problems(38). Most patients are not informed about sexual concerns, for example how treatment may affect sexuality, what the common problems are and what can be done(7). The majority of cancer patients believes that communication about sexuality with their healthcare provider is important and half of the patients report to be not satisfied with the communication and information received(39). Sexual health is a challenging topic to discuss in medical practice. Patients might face barriers like feelings of shame or lack of privacy to bring up the topic(10, 26, 40-43). Most healthcare professionals do feel responsible for bringing up the topic(44). They consider sexual health as important but experience barriers to discuss sexuality as well, like lack of knowledge and training, lack of time, feeling of shame, presence of a third party and illness of the patient(45-47). Literature reveals that sexual health is least likely to be discussed unless asked by the healthcare professional. Patients report they want that their healthcare professionals to provide information and help with sexual consequences of cancer treatment, as do their partners(24, 32, 34, 35). According to the literature, there is a need for improvement of information about sexuality for cancer patients and if applicable their partners(26, 32, 40, 42, 48-51).

Aim and outline of this thesis - Cancer and sexual health: the continuum of care

This thesis aims to evaluate the need and preferences of information and support regarding sexual health throughout patients' treatment process, follow-up and during survivorship. Since sexual problems can arise during each stage of treatment, follow-up and survivorship, it is an admirable goal to achieve integration of sexual health in the continuum of care for patients. Continuum of care is a concept involving an integrated system of care that maintains continuity of the medical care delivered to the patient from the diagnosis onwards(52).

In this thesis a distinction is made between patients, partners, healthcare professionals and the organization of health care - stakeholders which are involved in sexual health. In **Part I**, patients are evaluated regarding their preferences in sexual healthcare. **Part II and III**, aims to explore the view of the partner and healthcare provider. In **Part IV**, effectives of educational interventions for healthcare providers and recommendations for the organization of sexual health care will be explored. By involving different stakeholders, recommendations can be provided for patient-centered sexual healthcare while considering the role of healthcare professionals and the challenges within the healthcare system.

REFERENCES

1. World Health Organization, Sexual health issues [2 april 2020]. Available from: https://www.who.int/sexual-and-reproductive-health/sexual-health-issues/ [
2. Maslow A. A Theory of Human Motivation Psychological Psychological Review. 1943;40(4): 370-96.
3. Cleary V, Hegarty J. Understanding sexuality in women with gynaecological cancer. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2011;15(1):38-45.
4. Woods NF. Toward a holistic perspective of human sexuality: alterations in sexual health and nursing diagnoses. Holistic nursing practice. 1987;1(4):1-11.
5. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9.
6. World Health Organization. Defining sexual health 2006 [1 april 2020]. Available from: https://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/.
7. C Foster LC, A Richardson, H Pimperton, R Nash. Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice. Journal of Cancer Policy. 2018;15:92-5.
8. Maddams J, Utley M, Moller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. British journal of cancer. 2012;107(7):1195-202.
9. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. CA: a cancer journal for clinicians. 2019;69(1):7-34.
10. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. J Cancer Surviv. 2016;10(3):600-9.
11. Sun V, Grant M, Wendel CS, McMullen CK, Bulkley JE, Herrinton LJ, et al. Sexual Function and Health-Related Quality of Life in Long-Term Rectal Cancer Survivors. The journal of sexual medicine. 2016;13(7):1071-9.
12. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]. 2014;12(1):41-53.
13. Andersen BL, DeRubeis RJ, Berman BS, Gruman J, Champion VL, Massie MJ, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2014;32(15):1605-19.
14. Weaver KE, Forsythe LP, Reeve BB, Alfano CM, Rodriguez JL, Sabatino SA, et al. Mental and physical health-related quality of life among U.S. cancer survivors: population estimates from the 2010 National Health Interview Survey. Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology. 2012;21(11):2108-17.
15. Chang YC, Hu WY, Chang YM, Chiu SC. Changes in sexual life experienced by women in Taiwan after receiving treatment for breast cancer. International journal of qualitative studies on health and well-being. 2019;14(1):1654343.
16. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405.
17. Wettergren L, Kent EE, Mitchell SA, Zebrack B, Lynch CF, Rubenstein MB, et al. Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study. Psychooncology. 2017;26(10):1632-9.
18. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World journal of urology. 2006;24(4):423-8.

19. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(2):135-45.
20. Olsson M, Steineck G, Enskar K, Wilderang U, Jarfelt M. Sexual function in adolescent and young adult cancer survivors-a population-based study. J Cancer Surviv. 2018;12(4):450-9.
21. Szalda D, Schapira MM, Jacobs LA, Palmer SC, Vachani C, Metz J, et al. Survivorship Care Planning for Young Adults After Cancer Treatment: Understanding Care Patterns and Patient-Reported Outcomes. Journal of adolescent and young adult oncology. 2018;7(4):430-7.
22. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.
23. Sadovsky R, Basson R, Krychman M, Morales AM, Schover L, Wang R, et al. Cancer and sexual problems. The journal of sexual medicine. 2010;7(1 Pt 2):349-73.
24. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer Nurs. 2009;32(4):271-80.
25. Chatterjee R, Andrews HO, McGarrigle HH, Kottaridis PD, Lees WR, Mackinnon S, et al. Cavernosal arterial insufficiency is a major component of erectile dysfunction in some recipients of high-dose chemotherapy/chemo-radiotherapy for haematological malignancies. Bone marrow transplantation. 2000;25(11):1185-9.
26. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.
27. Reese JB, Haythornthwaite JA. Importance of sexuality in colorectal cancer: predictors, changes, and response to an intimacy enhancement intervention. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2016;24(10):4309-17.
28. Reisman Y, Gianotten W. Cancer, Intimacy and Sexuality. 1 ed: Springer International Publishing; 2017.
29. Lehto US, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. European journal of cancer care. 2018;27(1).
30. Oldertroen Solli K, de Boer M, Nyheim Solbraekke K, Thoresen L. Male partners' experiences of caregiving for women with cervical cancer-a qualitative study. Journal of clinical nursing. 2019;28(5-6):987-96.
31. Miaja M, Platas A, Martinez-Cannon BA. Psychological Impact of Alterations in Sexuality, Fertility, and Body Image in Young Breast Cancer Patients and Their Partners. Revista de investigacion clinica; organo del Hospital de Enfermedades de la Nutricion. 2017;69(4):204-9.
32. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.
33. Garos S, Kluck A, Aronoff D. Prostate cancer patients and their partners: differences in satisfaction indices and psychological variables. The journal of sexual medicine. 2007;4(5):1394-403.
34. Gilbert E, Ussher JM, Hawkins Y. Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. Health (London, England : 1997). 2009;13(5):523-41.
35. Mehta A, Pollack CE, Gillespie TW, Duby A, Carter C, Thelen-Perry S, et al. What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study. Sexual medicine. 2019;7(2):184-91.
36. Rottmann N, Gilsa Hansen D, dePont Christensen R, Hagedoorn M, Frisch M, Nicolaisen A, et al. Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. Acta oncologica (Stockholm, Sweden). 2017:1-8.
37. Kroenke CH, Michael YL, Poole EM, Kwan ML, Nechuta S, Leas E, et al. Postdiagnosis social networks and breast cancer mortality in the After Breast Cancer Pooling Project. Cancer. 2017;123(7):1228-37.

38. Walker LM, Wiebe E, Turner J, Driga A, Andrews-Lepine E, Ayume A, et al. The Oncology and Sexuality, Intimacy, and Survivorship Program Model: An Integrated, Multi-disciplinary Model of Sexual Health Care within Oncology. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
39. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.
40. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
41. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.
42. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. Social science & medicine (1982). 2007;64(8):1704-18.
43. Crowley SA, Foley SM, Wittmann D, Jagielski CH, Dunn RL, Clark PM, et al. Sexual Health Concerns Among Cancer Survivors: Testing a Novel Information-Need Measure Among Breast and Prostate Cancer Patients. Journal of cancer education : the official journal of the American Association for Cancer Education. 2016;31(3):588-94.
44. Hautamaki K, Miettinen M, Kellokumpu-Lehtinen PL, Aalto P, Lehto J. Opening communication with cancer patients about sexuality-related issues. Cancer nursing. 2007;30(5):399-404.
45. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.
46. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
47. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
48. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
49. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.
50. Jonker-Pool G, Hoekstra HJ, van Imhoff GW, Sonneveld DJ, Sleijfer DT, van Driel MF, et al. Male sexuality after cancer treatment--needs for information and support: testicular cancer compared to malignant lymphoma. Patient education and counseling. 2004;52(2):143-50.
51. Almont T, Couteau C, Etienne H, Bondil P, Guimbaud R, Schover L, et al. Sexual health and needs for sexology care in digestive cancer patients undergoing chemotherapy: a 4-month cross-sectional study in a French University Hospital. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018.
52. Evashwick C. Creating the continuum of care. Health matrix. 1989;7(1):30-9

PART I

THE PATIENT

Chapter 2: Discussing sexuality in cancer care: towards personalized information for cancer patients and survivors

Albers LF, van Belzen MA, van Batenburg C, Engelen V,
Putter H, Pelger RCM, Elzevier HW

Support Care Cancer 2020 Jan 2020 Sep;28(9):4227-4233

Introduction

The negative impact of cancer and cancer treatment on patients' sexuality is widely known(1-4). Cancer patients can experience sexuality related issues regardless of cancer type or treatment(5-7). Prevalence of sexuality related issues due to cancer is high and is reported up to 90% in some gynecologic cancers(8). The etiology of sexuality related issues in cancer patients is multifactorial(9). The cancer itself, cancer treatment, as well as psychological factors can contribute to the issues(8).

Sexuality related issues can arise by start of treatment and are likely to extend years after primary treatment(2, 10). Sexuality is considered an important quality of life concern by many cancer patients and survivors(11, 12). Since prognosis for cancer gets, attention directed towards the late effects of treatment and quality of life concerns is getting more important. An opportunity to discuss sexuality during the treatment process is important(4). Before treatment, cancer patients and physicians should be aware of potential sexual side effects of treatment. During treatment and follow-up communication is essential to identify and treat sexual problems(2, 10, 13). Most health care providers see sexuality as an important topic that need to be discussed(6, 14, 15). However, communication between patients and health care providers about sexuality is challenging and seems not enough imbedded in daily oncological practice yet(13, 15-19). Many barriers of health care professionals to initiate the discussion are described, like lack of time and lack of training(13, 20-24). Consequently, many cancer patients may experience unmet sexual health needs. Previous studies focused on the assessment of patients reported rates of communication about sexuality with health care providers and patients' experience with the communication. These studies reveal that cancer patients and survivors are not satisfied with current communication and the existing information regarding sexuality. The studies highlight the need for improvement of information about sexuality for cancer patients(17-19, 25-29). However, it is known that not all patients have the same need for information regarding sexuality(30). To our knowledge, only a few recent studies have examined which patients have a greater need for information about sexuality(16, 30). Moreover, preferences for kind of information might be personal and differ between cancer types.

Taking this in mind, personalized information for cancer patients and survivors is needed. The aims of the current study were to identify in a large sample of cancer patients what substantive information patients and survivors preferred to receive, their ideas on how to improve communication regarding sexuality, and to identify patients groups who are more in need of sexuality-related information.

Methods

Study population and procedure

The study was conducted by The Dutch Federation of Cancer Patient Organizations (NFK) and the Leiden University Medical Center (LUMC), the Netherlands. The NFK is the Dutch umbrella organization for cancer patient organizations. The NFK and the cancer patient organizations work together to promote important and relevant themes. Besides, they ask for attention for underexposed themes. Sexuality was considered as an underexposed theme in cancer care. This questionnaire survey was initiated by the NFK.

The questionnaire was sent to cancer patients and survivors of eight cancer patient organizations as well as patients in the patient panel of the NFK. The questionnaire was also open for cancer patients who were not a member of one of the organizations. The participants were recruited via the following channels: email to members, NFK website, NFK newsletter, websites and newsletters of the cancer patient organizations, and social media. The questionnaire was distributed in March 2017 and open for two weeks. Due to the wide distribution of the questionnaire, it was not possible to know a actual reach and response rate.

Questionnaire:

The questionnaires for the survey were developed by the NFK in collaboration with patients advocates and the department of Urology and department of Biomedical Data Sciences at the LUMC since no validated questionnaire for the aim of the study was available. Structure and design of the questionnaires were derived from questionnaires used in previous studies performed by the LUMC to evaluate sexual health care, with items based on issues identified by the authors and in literature(21, 23, 31, 32). Patient advocates' knowledge and experiences played a key role in matching the questionnaires to patients' needs and perspective.

The questionnaire contains 28 questions (see Appendix 2) assessing topics such as demographic factors, issues with sexuality after cancer, information needs regarding sexuality, and their ideas to improve communication about sexuality with a health care provider.

Privacy

All data were stored securely and only authorized employees of the NFK and a researcher of the LUMC had access to the data. No personal information of participants was collected. Questionnaires couldn't be traced back to the participants. This was confirmed by the privacy coordinator of the NFK.

Data-analysis

All data were analysed using IBM SPSS statistics 23. Demographic information and responses to the survey were analysed using descriptive statistics. Bladder cancer and kidney cancer and cancer of the male external genitalia were merged to “Urological cancer”. Type of cancers which were < 5% of the total group were merged to “other”. These included endocrine, haematological, lung, bone, head neck and skin malignancies. Difference in age between male and female was calculated using the independent sample T-test. Bivariate associations were calculated using the Pearson's chi-square test. Binary logistic regression model was used to predict the probability of needing information. Need for information was the dependent variable. The following covariates were included in the model: age (younger vs older, divided according to the median), gender (male vs. female), stage of disease (local vs. metastatic), relationship (no vs. yes), self-reported negative impact on sexuality (no vs. yes), time from diagnosis (<2 years, 3-5 years, 6-10 years, > 10 years), treatment modalities (all: no vs yes): surgery, external beam therapy, internal beam therapy, hormonal therapy, chemotherapy, immunotherapy. For the binary logistic regression stratified for type of cancer only the significant variables were presented. “Other” malignancies were not included in the model since this is a mix of 6 different malignancies. The models were built using backward selection based on Wald tests. Outcomes were considered statistically significant if the two-sided P- values were <0.05.

Ethics

The Medical Ethics Committee of the LUMC was consulted in order to verify whether ethical approval was necessary. Since the survey was initiated by the NFK in such a manner that the respondents could not be identified and participation was anonymous and fully voluntarily the Committee declared that no formal ethical approval was needed (protocol number G19.052).

Results

In total, 2657 (ex)cancer patients participated in the study. Half of the respondents was male (45%). Men (mean age 66.6 years, SD 10.3) were significant older than women (mean age 54.0 years, SD 11.4) ($p<0.001$, CI 95% 11.7-13.4, SE 0.4). The majority of respondents (89%) was in a relationship. Of all men, 44% (n=523) had prostate cancer. Of all women, 63% (n=902) had breast cancer. Of all respondents, 67% (n=1767) reported a negative impact of cancer on their sexuality. All characteristics are presented in **Table 1**.

Table 1: Patients characteristics (n=2657)
* Multiple answers possible

	Participants n (%)
Gender	
Male	1193 (45)
Female	1444 (55)
Age (years)	Median 61 (19-94 years)
Relationship status	
Not in a relationship	267 (11)
In a relationship	2221 (89)
Time since diagnosis	
≤ 2 year	530 (23)
3-5 year	736 (32)
6-10 year	556 (24)
> 10 year	471 (21)
Type of cancer*	
Breast	905 (34)
Prostate	531 (20)
Gastro-intestinal	455 (17)
Urological	172 (7)
Gynecological	135 (5)
Other	260 (10)
Stage of cancer	
Local disease	1708 (74)
Metastatic disease	477 (20)
Treatment*	
No treatment	29 (1)
Surgery	1954 (74)
External beam therapy	1205 (45)
Internal beam therapy	172 (7)
Hormonal therapy	791 (49)
Chemotherapy	1073 (40)
Immunotherapy	186 (7)
Self-reported negative impact of cancer on sexuality	
Yes	1767 (67)
No	884 (33)

Factors associated with a higher need for information

Of the respondents, 65% (n=1721) reported a need for information regarding sexuality. Patients with gynaecological cancer reported the highest need (n=113, 84%), followed by patients with prostate cancer (n=383, 72%), see **Figure 1**. Of the patients diagnosed with cancer less than two years as well as patients who were diagnosed 3-5 years ago, in both groups 71% reported a need for information (resp. n=377 and n=522). In patients who were diagnosed 6-10 years ago, 69% (n=384) reported a need, and a need was reported by 57% (n=269) in patient who were diagnosed more than 10 years ago.

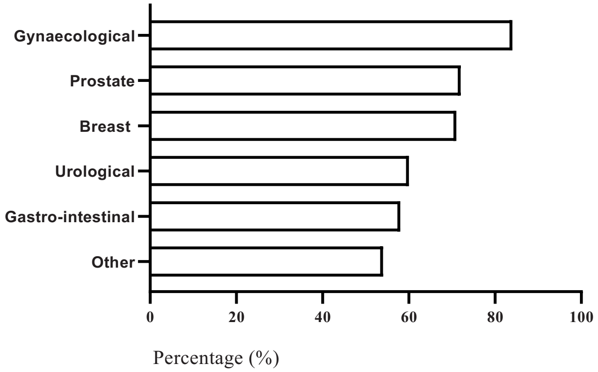


Figure 1: Percentage of patients who reported to have a need for information regarding sexuality

The need for information was significantly higher in patients from 61 years and younger ($p<0.001$), patients with a self-reported negative impact of cancer on sexuality ($p< 0.001$) and patients who were diagnosed less than two years ago ($p=0.04$). The need for information significantly declined after 10 years after diagnosis ($p=0.02$).

No differences in need for information according to gender, relationship status, stage of disease or treatment were found, see **Table 2**. **Table 3** shows that the need for information stratified for type of cancer. In contrast to the analyses with all respondents, the information need did not differ according to age in patients with a gynaecologic cancer. The information need in patient with prostate cancer was higher in patient who had surgery ($p=0.02$) and patient with a local stage of disease (<0.01).

Table 2: Factors associated with a higher need for information

Variable	**B***	**S.E.***	**P Value**
Age (≥62 years)	-.9	.1	<0.001
Gender	-.1	.1	0.6
Stage of disease	-.1	.1	0.3
Relationship	.2	.2	0.3
Negative impact on sexuality	1.6	.1	<0.001
Time from diagnosis			
< 2 years			0.04
2-5 years	.007	.1	0.9
6-10 years	-.07	.2	0.7
> 10 years	-.4	.2	0.02
Treatment			
Surgery	.01	.2	0.9
External beam therapy	.2	.1	0.2
Internal beam therapy	-.2	.2	0.4
Hormonal therapy	-.1	.1	0.6
Chemotherapy	-.1	.1	0.4
Immunotherapy	.2	.2	0.4

*B = regression coefficient, SE = standard error

Table 3: Factors associated with a higher need for information according to type of cancer

Variable	B*	S.E.*	P Value
Breast			
Age (≥54 years)	-.4	.2	0.04
Negative impact on sexuality (no vs. yes)	1.9	.2	<0.01
Prostate			
Age (≥70 years)	-1	.2	< 0.01
Negative impact on sexuality	.9	.3	< 0.01
Surgery (no vs. yes)	.5	.2	0.02
Stage of disease (local vs. metastatic)	-.9	.2	< 0.01
Gastro-intestinal			
Age (≥68 years)	-.6	.2	< 0.01
Negative impact on sexuality	1.5	.2	< 0.01
Urological			
Age (≥68 years)	-1.7	.4	<0.01
Negative impact on sexuality	.9	.4	0.03
Gynaecological cancer			
Negative impact on sexuality	1.5	.7	0.02

*B = regression coefficient, SE = standard error

What do they need?

Respondents, who reported a need for information regarding sexuality were asked what kind of information they prefer to receive. **Table 4** presents the scores of the need of specific kind of information. Patients do prefer to receive several types of information. Most mentioned were practical tips (n=1048, 60%), practical information (etiology, prevalence) (n=1018, 59%) and experiences from others (n=943, 54%).

Respondents, who reported a need for information, were asked how health care professionals could improve communication around sexuality. More than half of all respondents (64%, n=1101) suggested that it would be of help to improve the communication about sexuality with their care providers if the care providers give information systematically and if health care providers initiate the subject (34%, n=578). A third of the respondents (34%, n=591) would like to have the opportunity to get a referral to a sexologist. Active involvement of the partner when discussing the subject was suggested by 45% (n=657) of the respondents in a relationship.

Table 4: Kind of information patients prefer to receive

	All	**Breast**	**Prostate**	**Urological**	**Gastro-intestinal**	**Gynaecological**
Total	1721 (100)*	643 (100)	383 (100)	104 (100)	262 (100)	113 (100)
Practical tips	1048 (60)	519 (81)	258 (68)	67 (64)	150 (57)	71 (63)
Practical information	1018 (59)	456 (71)	198 (52)	49 (47)	142 (54)	71 (63)
Experiences from others	943 (54)	352 (55)	215 (56)	60 (58)	126 (48)	71 (63)
Information for partners	647 (37)	270 (42)	153 (40)	34 (33)	79 (30)	39 (35)
Contact with other cancer patients	298 (17)	112 (17)	61 (16)	18 (17)	38 (15)	23 (20)
Referral to a professional	281 (16)	97 (15)	70 (18)	22 (21)	49 (19)	19 (17)
Information video	141 (8)	30 (5)	58 (15)	12 (12)	24 (9)	7 (6)
Information for care providers	130 (8)	61 (10)	23 (6)	5 (5)	11 (4)	12 (11)

* Patients, out of all respondents, who reported to be in need of information regarding sexuality

Discussion

The aim of this study was to examine what kind of sexuality-related information cancer patients need, their ideas on how to improve communication regarding sexuality, and to identify groups who are likely to be more in need of information. It shows that cancer patients reported to be in need of different kind of information regarding sexuality. Respondents preferred practical tips and practical information regarding sexuality. Respondents emphasized the importance of care providers to provide information regarding sexuality as standard care. The study highlighted factors associated with a higher need for information regarding sexuality in terms of age, self-reported negative impact of cancer on sexuality and time from diagnosis.

Based on earlier research, patients experience unmet needs regarding sexual health care, including a lack of information and communication with health care providers about sexuality(17-19, 25-29). As respondents of the current survey recommended to health care providers, providing information regarding sexuality as standard care might create an opening for discussing sexuality and may therefore be used to enhance communication about sexuality (25, 33, 34). The availability of accurate information regarding sexuality might be helpful for health care providers to initiate a discussion. Some of health care providers' barriers for not initiating the topic, like lack of training in sexual issues or lack of resources, could be reduced if information is available. According to our survey, information should contain at least practical tips and information regarding sexuality to meet with patients' preferences. However, given the distribution of preferences of patients regarding kind of information, it would be ideal to provide multiform information.

In our survey 35% of the respondents reported to feel no need for information regarding sexuality. This percentage is in concordance with the literature(28, 35). Since sexuality is considered as a sensitive and private subject, it might be important to be aware of patients who are more likely to be in need. Age is one predictive factor in regard to information need.
According to the literature, in our survey younger patients reported a higher information need(18, 36). Younger patients are likely to have more sexual activity and therefore a higher need for information. However, age is not a defining factor since sexual activity continues to an old age and sexuality in older patients cannot be neglected (7, 16, 37, 38). Previous literature reported a higher percentage of men to discuss sexuality with a health care provider, suggesting a higher information need in men(16, 17, 30). However, the present study suggests that the need for information regarding sexuality does not differ between gender. Study results also suggest a higher need in patients diagnosed less than two years ago. Information should be provided actively to patients during this period. The need for information regarding sexuality declines significantly 10 year after diagnosis. However, 57% of the respondents who were diagnosed more than 10 years ago still reported a need for information. This indicates a role for information regarding sexuality in long time follow-up. Sexual issues can remain long time after diagnosis and not all cancer patients might be in follow-up when they face sexuality issues(10). Therefore, it is recommended to embed practical tips and information regarding sexuality not only in standard care and follow-up care but also make sure it is widely available and easily accessible online.

Our findings can contribute to the development and implementation of information to better inform and support cancer patient and survivors about sexuality issues. Unlike previous research, the current study assessed what kind of information patients with different kind of cancer prefer. This may contribute to more personalized information for cancer patients and survivors. The results of this study resulted in a Dutch website about cancer and sexuality with practical tips, practical information and experiences from others divided by cancer type (www.kankerenseks.nl).

Strengths of this study are the large sample size and the inclusion of patients with different cancer types and different times from diagnosis. Some limitations need to be considered. First, the study design was cross-sectional. The respondents were mainly recruited via the NFK and related patient organisations. It is unknown if the respondents are a representative sample of all cancer patients. Patient who have unmet sexual health care needs might more likely to respond. However, the need for information regarding sexuality in our study was comparable with previous literature(28, 35).
Second, level of education was not included in our questionnaire. A higher education level has shown to be associated with a higher health literacy and a better capability to assert needs(18, 39). Moreover, it can be argued that level of education may have an impact on preferences regarding kind of information(40). In general, members of patient organizations have a higher level of education than the population of cancer patients. Therefore, our results might not be generalizable for all cancer patients and patients' level of education should be incorporated in further research. Finally, recall bias might have occurred since a self-reported questionnaire was used. The majority of respondents was diagnosed more than two years ago. Experiences of respondents diagnosed some time ago are important to this study because sexual issues can remain in long term survival. Further research could focus on longitudinal evaluation of information designed according to patients' preferences.

Conclusion

According to these findings it can be concluded that cancer patient prefer different types of information about cancer induced sexuality issues. Most preferred information were practical tips and information, regardless of cancer type. (Ex)cancer patients prefer to get standard information provided by their health care providers. Patients' age, self-reported negative impact on sexuality and time from diagnosis (< 2 years) were related with a higher need of information regarding sexuality. Results might be useful for developing suitable information regarding sexuality for cancer patients in the future.

REFERENCES

1. Stabile C, Goldfarb S, Baser RE, Goldfrank DJ, Abu-Rustum NR, Barakat RR, et al. Sexual health needs and educational intervention preferences for women with cancer. Breast cancer research and treatment. 2017;165(1):77-84.
2. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9.
3. Sadovsky R, Basson R, Krychman M, Morales AM, Schover L, Wang R, et al. Cancer and sexual problems. The journal of sexual medicine. 2010;7(1 Pt 2):349-73.
4. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.
5. Katz A, Dizon DS. Sexuality After Cancer: A Model for Male Survivors. The journal of sexual medicine. 2016;13(1):70-8.
6. Dizon DS, Suzin D, McIlvenna S. Sexual health as a survivorship issue for female cancer survivors. The oncologist. 2014;19(2):202-10.
7. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. J Cancer Surviv. 2016;10(3):600-9.
8. Alappattu M, Harrington SE, Hill A, Roscow A, Jeffrey A. Oncology Section EDGE Task Force on Cancer: A systematic review of patient-reported measures for sexual dysfunction. Rehabilitation oncology (American Physical Therapy Association Oncology Section). 2017;35(3):137-43.
9. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9.
10. Raggio GA, Butryn ML, Arigo D, Mikorski R, Palmer SC. Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. Psychology & health. 2014;29(6):632-50.
11. Hansen DG, Larsen PV, Holm LV, Rottmann N, Bergholdt SH, Sondergaard J. Association between unmet needs and quality of life of cancer patients: a population-based study. Acta oncologica (Stockholm, Sweden). 2013;52(2):391-9.
12. Li WW, Lam WW, Au AH, Ye M, Law WL, Poon J, et al. Interpreting differences in patterns of supportive care needs between patients with breast cancer and patients with colorectal cancer. Psycho-oncology. 2013;22(4):792-8.
13. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.
14. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]. 2014;12(1):41-53.
15. Krouwel EM, Albers LF, Nicolai MPJ, Putter H, Osanto S, Pelger RCM, et al. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
16. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94.
17. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.
18. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.

19. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
20. Hautamaki K, Miettinen M, Kellokumpu-Lehtinen PL, Aalto P, Lehto J. Opening communication with cancer patients about sexuality-related issues. Cancer nursing. 2007;30(5):399-404.
21. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
22. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.
23. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
24. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.
25. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.
26. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. Social science & medicine (1982). 2007;64(8):1704-18.
27. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.
28. Jonker-Pool G, Hoekstra HJ, van Imhoff GW, Sonneveld DJ, Sleijfer DT, van Driel MF, et al. Male sexuality after cancer treatment--needs for information and support: testicular cancer compared to malignant lymphoma. Patient education and counseling. 2004;52(2):143-50.
29. Almont T, Couteau C, Etienne H, Bondil P, Guimbaud R, Schover L, et al. Sexual health and needs for sexology care in digestive cancer patients undergoing chemotherapy: a 4-month cross-sectional study in a French University Hospital. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018.
30. Hautamaki-Lamminen K, Lipiainen L, Beaver K, Lehto J, Kellokumpu-Lehtinen PL. Identifying cancer patients with greater need for information about sexual issues. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2013;17(1):9-15.
31. Nicolai MP, van Bavel J, Somsen GA, de Grooth GJ, Tulevski, II, Lorsheyd A, et al. Erectile dysfunction in the cardiology practice-a patients' perspective. American heart journal. 2014;167(2):178-85.
32. Marijnen CA, van de Velde CJ, Putter H, van den Brink M, Maas CP, Martijn H, et al. Impact of short-term preoperative radiotherapy on health-related quality of life and sexual functioning in primary rectal cancer: report of a multicenter randomized trial. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2005;23(9):1847-58.
33. Barbera L, Zwaal C, Elterman D, McPherson K, Wolfman W, Katz A, et al. Interventions to address sexual problems in people with cancer. Current oncology (Toronto, Ont). 2017;24(3):192-200.
34. Carter J, Lacchetti C, Andersen BL, Barton DL, Bolte S, Damast S, et al. Interventions to Address Sexual Problems in People With Cancer: American Society of Clinical Oncology Clinical Practice Guideline Adaptation of Cancer Care Ontario Guideline. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2018;36(5):492-511.

35. Den Ouden MEM, Pelgrum-Keurhorst MN, Uitdehaag MJ, De Vocht HM. Intimacy and sexuality in women with breast cancer: professional guidance needed. Breast cancer (Tokyo, Japan). 2018.

36. Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. Cancer nursing. 2002;25(1):42-9.

37. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World journal of urology. 2006;24(4):423-8.

38. Lindau ST, Gavrilova N. Sex, health, and years of sexually active life gained due to good health: evidence from two US population based cross sectional surveys of ageing. BMJ (Clinical research ed). 2010;340:c810.

39. Fleary SA, Joseph P, Pappagianopoulos JE. Adolescent health literacy and health behaviors: A systematic review. Journal of adolescence. 2018;62:116-27.

40. Tennant B, Stellefson M, Dodd V, Chaney B, Chaney D, Paige S, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. Journal of medical Internet research. 2015;17(3):e70.

Chapter 3: Sexual satisfaction in men suffering from erectile dysfunction after robot assisted radical prostatectomy for prostate cancer: an observational study

---

Albers LF, Tillier CN, Muilekom HAM, Elzevier HW, van Rhijn BW, Van der Poel HG, Hendricksen K

Journal of Sexual Medicine 2020 Dec 24;S1743-6095(20)31057-2

Introduction

Prostate cancer is the second most common cancer among men(1). Robot-assisted radical prostatectomy (RARP) is one of the recommended treatment options for localized prostate cancer with a long-term survival benefit(2). Given the expected long-term survival after RARP, functional outcomes are of utmost importance(3). The most common side-effect of RARP is erectile dysfunction (ED). Reported rates of ED after RARP range between 10 and90%. These wide ranges are due to differences in patient selection, surgical approaches and heterogeneous definitions of ED(4-6). ED is an important post-operative concern for patients, which is known to negatively impact quality of life(7). Additionally, ED is associated with anxiety, depressive symptoms, low self-esteem and diminished intimate relationships with the partner(3, 8). Despite refinement of nerve-saving operative techniques, the introduction of robotic surgery and the combination with penile rehabilitation programs(9, 10), a recent study failed to show an increased likelihood of erectile function recovery after RARP, in the last decade(11). Currently, a great deal of attention is being paid to predicting ED and the chances of long-term improvement of erectile function after RARP(12-16). The overall chance of having adequate erectile function after RARP has been reported to be 35%(17). The most well-known factors for improvement of erectile function include patient's age, comorbidities, nerve-sparing status and preoperative erectile function(18, 19). Information on the probability of improvement of erectile function is important when counseling patients about their expected erectile function and so that they can be offered support if needed.

Patients who reach their baseline erectile function will not necessarily regain sexual satisfaction(20). In addition to ED, sexual changes after RARP include loss of penile length, reduced sexual desire and orgasmic dysfunction including painful orgasm and climacturia (21-23). Some men reported that they did not find sexual changes problematic or they may cope successfully with such issues(24). Whether satisfaction with sexual life improves in patients with ED due to RARP has been less frequently investigated.

Primary objective of our study was to examine if overall satisfaction with sexual life of patients without ED before RARP and with ED after RARP improved over time. As secondary objective: exploration of factors which could be correlated with overall satisfaction during long-term follow-up in this group.

Material and methods

This is an observational study. All patients treated with RARP for localized prostate cancer, at a single center, between 2006 and 2019, were evaluated. Patients who underwent a RARP for prostate cancer were asked to fill in questionnaires prior to RARP and at 6-, 12- and 24-months' follow-up. From 2013 onwards, patients were also asked to fill in an additional at 36-months' follow-up. Questionnaires were provided via email or on paper. Patient-, tumor- and surgical characteristics were available from the prospectively maintained genito-urinary database at our hospital, including treatment and follow-up data.

The following questionnaires were used: the 'EORTC core quality of life questionnaire' (QLQ-C30), 'International Index of Erectile Function 15' (IIEF-15; containing five areas: erectile function, orgasmic function, sexual desire, intercourse satisfaction, overall satisfaction), 'International Prostate Symptom Score' (IPSS), 'International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form' (ICIQ-UI SF)(25-30).

In addition, the 'International Index of Erectile Function 5' (IIEF-5) was used to describe erectile function at baseline and during follow-up(min-max: 1-25). The IIEF-5 was the score most frequently filled in by the participants during follow-up to determine erectile function. Hence the IIEF-5 was used to define and categorize ED according the validated no ED (22-25), mild ED (17-21), mild-moderate ED (12-16), moderate ED (8-11), severe ED (1-7)(31). Patients were divided into two groups: (1) patients with mild or no ED (without ED, ≥17) and (2) patients with mild-moderate, moderate and severe ED (with ED, < 17) (26, 29).

The 'overall satisfaction'-score (the sum of Q13 and Q14) of the IIEF-15 questionnaire was used to describe overall satisfaction with sexual life. Q13 and Q14 have a 5-point Likert-scale; 1 indicating very dissatisfied and 5 very satisfied. Satisfaction was categorized as follows, 'satisfied' (overall satisfaction ≥8) or 'not satisfied' (overall satisfaction < 8) (26). The scores of the other subdomains of the IIEF-15 were used according to score guideline of the IIEF-15 questionnaire (26). The score on 'quality of life' (QoL) was calculated from the QLQ-C30 according to the EORTC QLQ-C30 Scoring Manual(32).

Differences between patients with ED who were satisfied and not satisfied were calculated at 24-months and 36-months' follow-up since it is known that erectile function can still improve up to 24 months and beyond (13, 33) after surgery. Patients without ED after RARP were used as control group.

Fascia preservation score (FP score) was used as scoring system for perioperative nerve sparing(34). The score accounts for the full circular distribution of the periprostatic nerves via a 12-tier score. FP score is described as a predictor of postoperative erectile function (16).

Statistics
All analyses were conducted using IBM SPSS Statistics 25. Patient, tumor and surgical characteristics were described using demographic statistics. The means and standard deviations of questionnaire outcomes were reported. To test for differences in overall satisfaction between time-points (baseline, 6, 12, 24, 36 months) and difference between overall satisfaction of patients with ED and without ED after RARP, a mixed effect model was used with a random intercept per patient. For differences of patients who were 'satisfied' and those who were 'not satisfied' at 24-months and 36-months, the Mann-Whitney U test was used. Median and interquartile range (IQR) were reported. The variables that were significant at the 0.05 level were then used to predict the satisfaction in separate simple logistic models in the subgroups with and without ED at 24-months and 36-months. Age, quality-of-life score, IIEF-5 score, sexual desire (IIEF-15), and overall satisfaction score (IIEF-15) at baseline were entered as explanatory variables. P-value < 0.05 was considered statistically significant.

Ethics
Institutional review board (number IRBd19226) approval of the Netherlands Cancer Institute - Antoni van Leeuwenhoek Hospital was obtained.

Results

Demographics
2808 patients treated with RARP for localized prostate cancer between 2006 and 2019 were evaluated. Patients with ED before RARP (n=1281) and patients with unknown erectile function before RARP (n=643) were excluded. 884 patients reported to have no ED before RARP and were included for analysis. All were sexually active before RARP. Their characteristics are presented in **Table 1**.
Next, we divided them into a group of patients with ED due to RARP to compare to those who had no ED after RARP. Data were available for 467, 381, 333 and 189 patients with ED due to RARP at 6-mo, 12-mo, 24-mo and 36-mo follow-up. For patients without ED after RARP, data were available for 93, 124, 168 and 72 patients at 6-mo, 12-mo, 24-mo and 36-mo follow-up, respectively. All patients without ED were sexually active during follow-up. Categorization of ED by different time-points is presented in **Table 2**.

Table 1. Patient characteristics of patients without ED before RARP (n=884)

Age in years, median (IQR)	63.0 (9)
PSA-level (ng/mL), median (IQR)	8.1 (6.1)
Clinical T-stage	
- cT0 (%)	219 (25%)
- cT2 (%)	505 (57%)
- cT3 (%)	152 (17%)
- cT4 (%)	1 (0.1%)
- Missing	6 (0.9%)
Pathological Gleason sum score	
- 5-6 (%)	189 (21.4%)
- 7: 3+ 4 (%)	364 (41.2%)
- 7: 4+3 (%)	143 (16.2%)
- 8-10 (%)	103 (11.7%)
- Missing	85 (9.5%)
Pathological N-stage	
- pN0 (%)	400 (45.2%)
- pN1 (%)	90 (10.2%)
- pNx (%)	360 (40.7%)
- Missing	34 (3.8%)
Intraoperative techniques	
Fascia preservation score (mean)	4.54 (range 0-12), SD 3.0
Pelvic lymph node dissection	
Yes	501 (56.6%)
No	371 (42.0%)
Missing	11 (1.4%)
Quality-of-life data	
IIEF-5 score	22.8 (17-25), SD 2.3
Quality-of-life score	81.6 (0-100), SD 17.4
IPSS score	5.5 (0-31), SD 6.6
ICIQ incontinence score	1.3 (0-16), SD 2.6

ED=erectile dysfunction; RARP=robot assisted radical prostatectomy; IQR=interquartile range;
SD=standard deviation; IIEF-5=international index of erectile function; IPSS=International Prostate Symptom Score; ICIQ=International Consultation on Incontinence questionnaire

Table 2: Categorization by timepoint of erectile dysfunction (ED) of the patients included for analysis

	Categories of ED				
	No % (n)	Mild % (n)	Mild-moderate % (n)	Moderate % (n)	Severe % (n)
Timepoints (months)					
0	73.8 (652)	26.2 (232)	*Not applicable*	*Not applicable*	*Not applicable*
6	8.2 (46)	8.4 (47)	9.5 (53)	13.2 (74)	57.3 (340)
12	14.5 (73)	10.1 (51)	10.9 (55)	12.1 (61)	52.5 (265)
24	18.0 (90)	15.6 (78)	9.0 (45)	11.4 (57)	46.1 (231)
36	14.9 (39)	12.6 (33)	10.3 (27)	10.0 (26)	52.1 (136)

Satisfaction

The mean overall satisfaction of patients without ED at baseline was 8.2 (range 2-10, SD 1.7). Patients with ED due to RARP had a mean overall satisfaction of 4.8, 4.8, 4.9 and 4.6 (range 2-10, SD 1.7-2.5, p=0.2) at 6, 12, 24 and 36 months' follow-up, respectively. The patients without ED after RARP had a mean overall satisfaction of 8.4, 8.4, 8.1 and 8.2 (range 3-10, SD 1.4 – 1.6, p=0.2) at 6, 12, 24 and 36 months' follow-up, respectively (**Figure 1**). Scores of patients between patients with and without ED were significantly different (p<0.01). Scores of the other subdomains of the IIEF-15 (erectile function, orgasmic function, sexual desire and intercourse satisfaction) are provided in the supplemental information section (appendix 3).

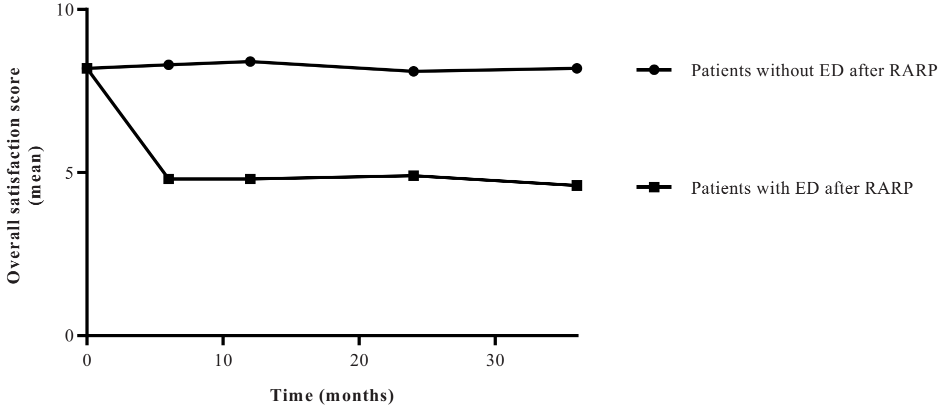


Figure 1: Sexual satisfaction score (range 2-10)

Differences between patients with ED who were satisfied and not satisfied with sexual life
Patients with ED at 24 months' follow-up, who were satisfied with sexual life at that moment, were compared to those with ED at 24 months who at that time were not satisfied with sexual life. Patients who were satisfied had a significant higher overall satisfaction score at baseline, Quality-of-life-score, IIEF-5 score and sexual desire score compared to patients who were not satisfied (**Table 3;** p-values varied between <0.01 and 0.03). Age, erectile function score at baseline, IPSS, incontinence score and FP score were not found to be associated (**Table 3,** p-values varied between 0.05 and 0.8). In a multiple logistic regression, overall satisfaction at baseline (OR 1.4, 95% CI 1.1-1.8, p=0.01) and sexual desire score at 24-mo (OR 1.7, 95% CI 1.4-2.1, p<0.01) were independent predictors of overall satisfaction in patients with ED at 24 months' follow-up (**Figure 2).**

The same was calculated at 36 months' follow-up. Patients with ED at 36 months' follow-up who were satisfied had a significantly higher overall satisfaction score at baseline, IIEF-5 score and sexual desire score compared to those who were not satisfied (**Table 3;** p-values varied between <0.01 and 0.06)**.** In a multiple logistic regression at 36-months' follow-up, the same predictors were found as at 24-months: overall satisfaction at baseline(OR 2.3, 95% CI 1.13-4.88, p=0.02) and sexual desire score at 36-mo (OR 2.1, 95% CI 1.20-3.75, p=0.09) (**Figure 2**).

Probability of being satisfied was significantly lower in patients with ED due to RARP compared to patients without ED after RARP, both at 24 months and at 36 months' follow-up (p<0.01) (**Figure 2**).

Table 3: Differences at 24-months and 36-months follow-up

Variable	**Follow-up**	**Satisfied** *mean (n, SD)*	**Not satisfied** *mean (n, SD)*	*p-value*
Age in years	24-mo	63.1 (70, 5.6)	63.0 (254, 5.6)	0.8
	36-mo	63.6 (27, 5.7)	62.8 (158, 5.6)	0.6
IIEF-5 score at baseline (range 17-25)	24-mo	22.5 (69, 2.8)	22.6 (252, 2.2)	0.7
	36-mo	22.0 (27, 3.0)	22.7 (156, 2.4)	0.4
Overall satisfaction score at baseline (range 2-10)	24-mo	8.9 (69, 1.4)	7.8 (250, 1.8)	*<0.01*
	36-mo	8.6 (27, 1.7)	7.9 (154, 1.8)	*0.02*
QoL score (range 0 – 100)	24-mo	85.9 (57, 13.5)	78,6 (180, 16.7)	*0.04*
	36-mo	79.8 (12, 10.9)	77.8 (66, 15.5)	0.6
IIEF-5 score (range 17-25)	24-mo	8.5 (70, 4.8)	5,2 (254, 4.2)	*<0.01*
	36-mo	8.1 (27, 4.8)	5.1 (158, 4.2)	*<0.01*
Incontinence score (range 0-21)	24-mo	2.7 (67, 3.0)	3.9 (249, 3.9)	0.3
	36-mo	3.5 (25, 3.5)	4.0 (154, 4.2)	0.5
IPSS (range 0-35)	24-mo	3.1 (59, 4.0)	3.8 (187, 4.5)	0.5
	36-mo	3.2 (15, 4.1)	3.7 (81, 5.0)	0.6
Sexual desire score (range 2-10)	24-mo	7.1 (70, 1.9)	5.2 (252, 1.9)	*<0.01*
	36-mo	7.1 (26, 1.6)	5.0 (158, 1.9)	*<0.01*
FP score (range 0-12)	24-mo	3.7 (70, 3.3)	3.9 (254, 2.8)	0.4
	36-mo	3.6 (27, 3.0)	4.0 (158, 2.9)	0.5

Mo=months; IQR=interquartile range; IIEF-5=international index of erectile function;

QoL= quality-of-life; IPSS = International Prostate Symptom Score; FP=fascia preservation

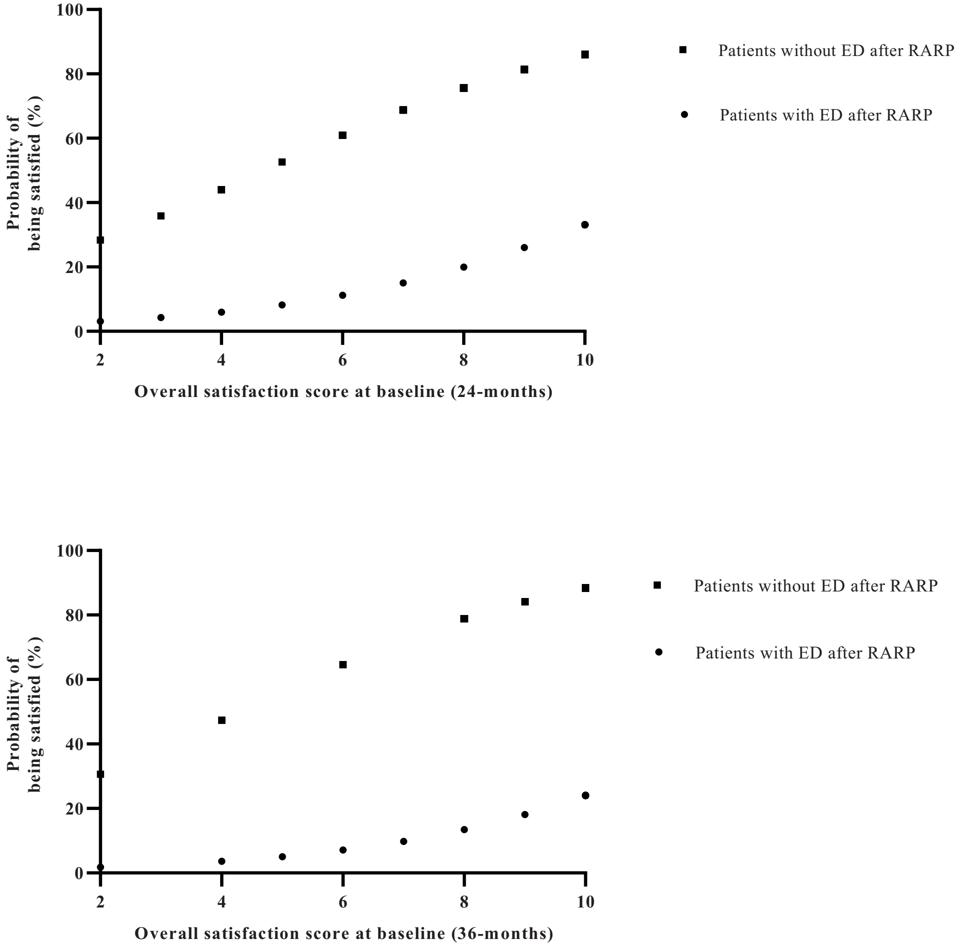


Figure 2: Probability of being sexual satisfied by overall satisfaction score at baseline (range 2-10), at 24-mo (above) and 36-mo follow-up (below)
** Satisfaction is a subscore of the IIEF-15*

Discussion

The goal of our study was to investigate if overall satisfaction with sexual life of patients with ED due to RARP improved over time, and to identify factors associated with satisfaction. We found no increase or decrease in overall satisfaction with sexual life between 6-months and 36-months' follow-up. A higher overall satisfaction score at baseline and a higher score on sexual desire were associated with satisfaction at 24- and 36 months' follow-up. Erectile function score was not correlated with overall satisfaction in this group. A high satisfaction rate was observed for men with erectile function preservation after prostatectomy.

In literature, several variables were found to be associated with sexual satisfaction: sexual desire, erectile function, sexual self-esteem, age, time since diagnoses, relationship variables and psychological variables like depression and anxiety(20, 24, 35-38). In contrast to our study, no other study evaluated satisfaction specifically in prostate cancer patients with ED due to RARP. In a study among Scandinavian prostate cancer patients who were treated with different modalities, longer time since diagnosis was associated with higher sexual satisfaction(35). The mean time since diagnosis was 6.1 years. In our study, overall satisfaction with sexual life score did not increase during follow-up. It can be argued that adjustment to or acceptance of new sexual function and sexual satisfaction may take longer than 3 years. In a prospective study, Dubbelman et al. found no significant difference between satisfaction scores 3 months and 5 years after radical prostatectomy(36). These findings indicate that improvement of sexual satisfaction of patients with ED due to RARP might occur over a long period of time. Additionally, depressive symptoms occur for a longer follow-up period postoperatively and may impact sexual functioning for a longer period of time. Depressive symptoms may contribute to delay in improvement of sexual satisfaction in patients with ED due to RARP (38, 39).

In our study, we found no relation between overall satisfaction and age in the cohort of patients with ED due to RARP. The Scandinavian study described above found that higher age was associated with an increase in sexual satisfaction in sexually active patients(35). It is known that sexual activity declines with age(40). People who are sexually active at an older age may well have continued their sexual activity because of greater sexual satisfaction and because they were able to cope with sexual changes. If this is the case, it would the idea that the satisfaction score at baseline is important for satisfaction after treatment.

Similar to Badr et al.'s findings in their cross-sectional study among prostate cancer patients treated with different modalities, we also report that a higher score on sexual desire was associated with greater sexual satisfaction(41). In contrast, Bravi et al. found that prostate cancer patients, treated with RARP, who had a high desire, found low erectile function to be more sexually problematic than patients with lower desire(24). On the other hand, men with satisfactory erections after RARP can also experience sexual problems, and men with impotence can be satisfied with their sexual life. This may indicate that erectile function may be not the most important part of overall satisfaction with sexual life (20, 37, 42-44). We believe it might be helpful to ask patients about sexual desire and sexual satisfaction during sexual counseling, rather than counselling them only about erectile function.

Although, erectile function is associated with increased sexual satisfaction, male sexuality is not exclusively associated with erections. We found that preoperative satisfaction is more important for postoperative sexual satisfaction than erectile function at baseline or at 24-/36-months' follow-up. Besides penile rehabilitation for ED, psychological interventions focusing on adjustment to the changes in sexual functioning and other forms of (physical) intimacy might improve sexual satisfaction; especially for those men who continue to suffer from ED.

Some limitations should be considered. Our results must be interpreted within the limits of retrospectively collected, observational data. We only included patients treated by RARP and therefore our results may be not representative of other treatment modalities. Further, we did not take into account the possible negative effect of adjuvant or salvage radiotherapy and androgen deprivation. Excluding these cases would have strengthened our conclusions. However, it can be argued that, if these additional treatments affected sexual satisfaction, sexual satisfaction would decrease over time. Overall satisfaction, however, remained constant in our study. ED is known to be a predictor of depressive symptoms(38). Further research could include a questionnaire on depressive symptoms to investigate their impact on sexual satisfaction after RARP. Despite these limitations, our results add important new insights into sexual satisfaction in patients with ED due to RARP. The large sample-size, use of multiple validated questionnaires and three years' follow-up are the strengths of our study.

Conclusion

Satisfaction with sexual life in men with ED due to RARP did not improve between 6 and 36 months' follow-up, indicating improvement of satisfaction might take a long time. One could counsel patients that sexual satisfaction is based on individual baseline sexual satisfaction and the return of sexual desire after RARP. It is vital to present realistic, individualized expectations regarding both sexual satisfaction and recovery after RARP.

REFERENCES

1. Culp MB, Soerjomataram I, Efstathiou JA, Bray F, Jemal A. Recent Global Patterns in Prostate Cancer Incidence and Mortality Rates. European urology. 2020;77(1):38-52.
2. Prostate Cancer Guidelines, European Association of Urology [1 December 2019]. Available from: https://uroweb.org/guideline/prostate-cancer/#note_375.
3. Vickers A, Bennette C, Steineck G, Adami HO, Johansson JE, Bill-Axelson A, et al. Individualized estimation of the benefit of radical prostatectomy from the Scandinavian Prostate Cancer Group randomized trial. European urology. 2012;62(2):204-9.
4. Bill-Axelson A, Holmberg L, Garmo H, Taari K, Busch C, Nordling S, et al. Radical Prostatectomy or Watchful Waiting in Prostate Cancer - 29-Year Follow-up. The New England journal of medicine. 2018;379(24):2319-29.
5. Ficarra V, Novara G, Artibani W, Cestari A, Galfano A, Graefen M, et al. Retropubic, laparoscopic, and robot-assisted radical prostatectomy: a systematic review and cumulative analysis of comparative studies. European urology. 2009;55(5):1037-63.
6. Mulhall JP. Defining and reporting erectile function outcomes after radical prostatectomy: challenges and misconceptions. The Journal of urology. 2009;181(2):462-71.
7. Whiting PF, Moore TH, Jameson CM, Davies P, Rowlands MA, Burke M, et al. Symptomatic and quality-of-life outcomes after treatment for clinically localised prostate cancer: a systematic review. BJU international. 2016;118(2):193-204.
8. Hedestig O, Sandman PO, Tomic R, Widmark A. Living after radical prostatectomy for localized prostate cancer: a qualitative analysis of patient narratives. Acta oncologica (Stockholm, Sweden). 2005;44(7):679-86.
9. Teloken P, Mesquita G, Montorsi F, Mulhall J. Post-radical prostatectomy pharmacological penile rehabilitation: practice patterns among the international society for sexual medicine practitioners. The journal of sexual medicine. 2009;6(7):2032-8.
10. Briganti A, Di Trapani E, Abdollah F, Gallina A, Suardi N, Capitanio U, et al. Choosing the best candidates for penile rehabilitation after bilateral nerve-sparing radical prostatectomy. The journal of sexual medicine. 2012;9(2):608-17.
11. Capogrosso P, Vertosick EA, Benfante NE, Eastham JA, Scardino PJ, Vickers AJ, et al. Are We Improving Erectile Function Recovery After Radical Prostatectomy? Analysis of Patients Treated over the Last Decade. European urology. 2019;75(2):221-8.
12. Huynh LM, Osann K, Skarecky D, Ahlering TE. Predictive modelling of 2-year potency outcomes using a novel 90-day erection fullness scale after robot-assisted radical prostatectomy. BJU international. 2018;122(2):249-54.
13. Mulhall JP, Kattan MW, Bennett NE, Stasi J, Nascimento B, Eastham J, et al. Development of Nomograms to Predict the Recovery of Erectile Function Following Radical Prostatectomy. The journal of sexual medicine. 2019;16(11):1796-802.
14. Alenizi AM, Zorn KC, Bienz M, Rajih E, Hueber PA, Al-Hathal N, et al. Erectile function recovery after robotic-assisted radical prostatectomy (RARP): long term exhaustive analysis across all preoperative potency categories. The Canadian journal of urology. 2016;23(5):8451-6.
15. Garcia FJ, Violette PD, Brock GB, Pautler SE. Predictive factors for return of erectile function in robotic radical prostatectomy: case series from a single centre. International journal of impotence research. 2015;27(1):29-32.
16. KleinJan GH, Sikorska K, Korne CM, Brouwer OR, Buckle T, Tillier C, et al. A prediction model relating the extent of intraoperative fascia preservation to erectile dysfunction after nerve-sparing robot-assisted radical prostatectomy. Journal of robotic surgery. 2019;13(3):455-62.
17. Salonia A, Adaikan G, Buvat J, Carrier S, El-Meliegy A, Hatzimouratidis K, et al. Sexual Rehabilitation After Treatment for Prostate Cancer-Part 1: Recommendations From the Fourth International Consultation for Sexual Medicine (ICSM 2015). The journal of sexual medicine. 2017;14(3):285-96.
18. Rabbani F, Stapleton AM, Kattan MW, Wheeler TM, Scardino PT. Factors predicting recovery of erections after radical prostatectomy. The Journal of urology. 2000;164(6):1929-34.

19. Nelson CJ, Scardino PT, Eastham JA, Mulhall JP. Back to baseline: erectile function recovery after radical prostatectomy from the patients' perspective. The journal of sexual medicine. 2013;10(6):1636-43.
20. Rossi MS, Moschini M, Bianchi M, Gandaglia G, Fossati N, Dell'Oglio P, et al. Erectile Function Recovery After Nerve-Sparing Radical Prostatectomy for Prostate Cancer: Is Back to Baseline Status Enough for Patient Satisfaction? The journal of sexual medicine. 2016;13(4):669-78.
21. Messaoudi R, Menard J, Ripert T, Parquet H, Staerman F. Erectile dysfunction and sexual health after radical prostatectomy: impact of sexual motivation. International journal of impotence research. 2011;23(2):81-6.
22. Frey A, Sonksen J, Jakobsen H, Fode M. Prevalence and predicting factors for commonly neglected sexual side effects to radical prostatectomies: results from a cross-sectional questionnaire-based study. The journal of sexual medicine. 2014;11(9):2318-26.
23. Capogrosso P, Ventimiglia E, Serino A, Stabile A, Boeri L, Gandaglia G, et al. Orgasmic Dysfunction After Robot-assisted Versus Open Radical Prostatectomy. European urology. 2016;70(2):223-6.
24. Bravi CA, Tin A, Montorsi F, Mulhall JP, Eastham JA, Vickers AJ. Erectile Function and Sexual Satisfaction: The Importance of Asking About Sexual Desire. The journal of sexual medicine. 2019.
25. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. Journal of the National Cancer Institute. 1993;85(5):365-76.
26. Rosen RC, Riley A, Wagner G, Osterloh IH, Kirkpatrick J, Mishra A. The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. Urology. 1997;49(6):822-30.
27. Barry MJ, Fowler FJ, Jr., O'Leary MP, Bruskewitz RC, Holtgrewe HL, Mebust WK, et al. The American Urological Association symptom index for benign prostatic hyperplasia. The Measurement Committee of the American Urological Association. The Journal of urology. 1992;148(5):1549-57; discussion 64.
28. Hajebrahimi S, Nourizadeh D, Hamedani R, Pezeshki MZ. Validity and reliability of the International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form and its correlation with urodynamic findings. Urology journal. 2012;9(4):685-90.
29. Utomo E, Blok BF, Pastoor H, Bangma CH, Korfage IJ. The measurement properties of the five-item International Index of Erectile Function (IIEF-5): a Dutch validation study. Andrology. 2015;3(6):1154-9.
30. Badía X, García-Losa M, Dal-Ré R. Ten-language translation and harmonization of the International Prostate Symptom Score: developing a methodology for multinational clinical trials. European urology. 1997;31(2):129-40.
31. Rhoden EL, Teloken C, Sogari PR, Vargas Souto CA. The use of the simplified International Index of Erectile Function (IIEF-5) as a diagnostic tool to study the prevalence of erectile dysfunction. International journal of impotence research. 2002;14(4):245-50.
32. EORTC QLQ-C30 Scoring Manual, Third Edition 2001, available from https://www.eortc.org/app/uploads/sites/2/2018/02/SCmanual.pdf [1 December 2020].
33. Alemozaffar M, Regan MM, Cooperberg MR, Wei JT, Michalski JM, Sandler HM, et al. Prediction of erectile function following treatment for prostate cancer. Jama. 2011;306(11):1205-14.
34. van der Poel HG, de Blok W. Role of extent of fascia preservation and erectile function after robot-assisted laparoscopic prostatectomy. Urology. 2009;73(4):816-21.
35. Martin Hald G, Dahl Pind M, Borre M, Lange T. Scandinavian Prostate Cancer Patients' Sexual Problems and Satisfaction With Their Sex Life Following Anti-Cancer Treatment. Sexual medicine. 2018;6(3):210-6.
36. Dubbelman YD, Wildhagen MF, Dohle GR. Penile vascular evaluation and sexual function before and after radical retropubic prostatectomy: 5-year follow-up. International journal of andrology. 2008;31(5):483-9.

37. Terrier JE, Masterson M, Mulhall JP, Nelson CJ. Decrease in Intercourse Satisfaction in Men Who Recover Erections After Radical Prostatectomy. The journal of sexual medicine. 2018;15(8):1133-9.

38. Boeri L, Capogrosso P, Ventimiglia E, Cazzaniga W, Pederzoli F, Gandaglia G, et al. Depressive Symptoms and Low Sexual Desire after Radical Prostatectomy: Early and Long-Term Outcomes in a Real-Life Setting. The Journal of urology. 2018;199(2):474-80.

39. Nelson CJ, Mulhall JP, Roth AJ. The association between erectile dysfunction and depressive symptoms in men treated for prostate cancer. J Sex Med. 2011;8(2):560-6.

40. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World journal of urology. 2006;24(4):423-8.

41. Badr H, Taylor CL. Sexual dysfunction and spousal communication in couples coping with prostate cancer. Psycho-oncology. 2009;18(7):735-46.

42. Nelson CJ, Deveci S, Stasi J, Scardino PT, Mulhall JP. Sexual bother following radical prostatectomyjsm. The journal of sexual medicine. 2010;7(1 Pt 1):129-35.

43. Fode M, Serefoglu EC, Albersen M, Sønksen J. Sexuality Following Radical Prostatectomy: Is Restoration of Erectile Function Enough? Sexual medicine reviews. 2017;5(1):110-9.

44. Warkentin KM, Gray RE, Wassersug RJ. Restoration of satisfying sex for a castrated cancer patient with complete impotence: a case study. Journal of sex & marital therapy. 2006;32(5):389-99.

PART II

THE PATIENT AND THEIR PARTNER

Chapter 4: Sexual healthcare for intimate partners of people with cancer: information and communication needs

---

Albers LF, van Belzen MA, van Batenburg C, Engelen V,
Putter H, den Ouden MEM, Pelger RCM, Elzevier HW

Journal of Sex & Marital Therapy. 2020 Nov 5;1-7

Introduction

Cancer and its treatment can negatively affect sexuality and intimacy, resulting in a decreased quality of life of patients with cancer (1-4). Sexual changes can start at diagnostic stage and are likely continue in long-term survival (1). Besides negative impact on patients sexuality and intimacy, most partners of patients with cancer report a negative impact on their sexuality and intimacy (5-10). Partners mark changes in their sexual relationship and a decreased frequency of sexual activity and intimacy. Previous studies identified the following reasons: the impact of cancer on self-image of the patient, physical changes, adverse effects of cancer treatment (e.g. pain, fatigue) and repositioning their partners as asexual (5, 7, 11). Consequently, partners report feelings of frustration, sadness and deterioration of their intimate relationship (11, 12). Nevertheless, an intimate relationship during cancer treatment and survivorship is important since it is associated with better psychosocial outcomes in both cancer patients and partners (13, 14).

Partners of patients with cancer experience communication with a care provider about sexuality and intimacy as unhelpful (9). They report a lack of advice and information regarding sexuality and intimacy issues (5, 9, 11, 12). They want a better insight in the sexual side effects and support on maintaining intimacy (5, 7, 15). Existing studies highlight the importance of involvement of the partner in communication about sexuality and intimacy with healthcare providers and providing them accurate information and include advice in supportive care for partners (5, 9, 11, 12, 16).

Little is known on partners' needs and preferences regarding communication about sexuality and intimacy. Moreover, to our knowledge, no recent studies have identified partners who are likely to be more in need of information. The aims of this study are to: 1) identify aspects that are associated with partners' sexuality and intimacy, 2) identify partners' characteristics that are associated with need for information, and 3) investigate partners' preferences for communication regarding sexuality and intimacy.

Methods

Study design

The survey was initiated by The Dutch Federation of Cancer Patient Organizations (NFK). Partners of patients with cancer were recruited via patients with cancer. First, the patients with cancer were recruited via different ways: an email to members of eight cancer patients organizations in the Netherlands, a call at the newsletters and website and of the NFK and allied cancer patient organizations, and via social media. By doing so, cancer patients and partners who were not a member of one of the cancer organizations were also able to react. The results of survey among cancer patients are out of the scope of this manuscript and are described elsewhere (17). The survey was open in March 2017. Responding cancer patients were requested to fill out the email address of their partner, if they wished their partner to receive the questionnaire of the current study. A different questionnaire was sent to the partners. Due to privacy reasons, it was not possible to relate the questionnaire of the cancer patients to the questionnaire of their partner. No reminder was sent. No data of the non-responders are available. There were no restrictions based on age, cancer diagnosis type or time since diagnosis. Sample size of the study could not be calculated due to the lack of previous and similar studies or surveys.

Questionnaire:
There was no validated questionnaire available. The questionnaire was conducted by the NFK in cooperation with the Leiden University Medical Center (LUMC) and patients advocates and their partners, based on the literature . The used questionnaire was based on questionnaires used in previous research of the LUMC. Items were based on expert opinions and literature (17-20). Patient advocates and partners were involved in the development of the questionnaire.

The questionnaire consists of 28 questions (see Appendix 4) including the following issues: demographics, concerns with sexuality and intimacy, information needs, and their suggestions to enhance communication regarding sexuality and intimacy with healthcare providers.

Statistics
Analysis were performed using IBM SPSS statistics 25. Descriptive statistics were used to analyse demographic information. Cancer types of the partners of the respondents which were less than 5% of the total amount were combined in "other". The independent sample T-test was used to calculate differences of numeric variables. Bivariate associations were tested with Pearson's chi-square test. For predication of the probability of the need of information a binary logistic regression was performed with need for information as dependent variable. Covariates which were included are: gender, age (divided by the median), disease stage, reported effect of cancer on sexuality, treatment modalities and time since diagnosis (less than 2 years, 3 till 5 years, 6 till 10 years and more than 10 years). Backward selection based on Wald tests was used. Types of information which were < 10% of the total amount were not displayed in Table 1. Missing data (questions which were not completed) was not added within the percentage; number (n) is mentioned to define. Statistical significant was considered if P- values were <0.05.

Privacy & ethics
The data was collected and stored by the NFK. Authorized staff members of the NFK and one staff member of the LUMC and author (LA) had access to the data. Questionnaires were collected anonymously and cannot be linked to the respondents. This was verified by a privacy staff member of the NFK.

The Medical Ethics Committee of the LUMC was consulted in order to verify whether ethical approval was necessary. Since the survey was initiated and conducted by the NFK, the respondents could not be identified and the participation was voluntarily and anonymous, the Medical Ethics Committee declared that no formal ethical approval was needed (protocol number G19.052). The current study was a continuation of a study among cancer patients and considered by the ethical committee at the same time with the same protocol number(17).

Results

In total, 564 partners of patients with cancer were invited to participate. 230 partners filled out the questionnaire, resulting in a response rate of 40%. **Table 1** presents the characteristics of the respondents. Of them, 66.3% (n=129) were female and 43.7% (n=100) were male. Female respondents (mean age 64.1, SD 9.9) were older than male respondents (mean age 58.8, SD 10.4) ($p< 0.001$). The majority of their partners had limited disease (n=151, 79.0%) and had undergone surgery (n=157, 68.3%).

Aspects associated with partners' sexuality and intimacy

Slightly more than half of the participants (n=127, 55.9%) stated that the cancer had negatively their sexuality and intimacy. Significantly more women (n=82, 64.6%) than men (n=45, 45.0%) reported this negative impact ($p< 0.01$). Three-quarter (n=47, 74.6%) of the partners of prostate cancer patients, 57.1% (n=32) of the partners of breast cancer patients and 56.5% (n=29) of the partners of patients with gastro-intestinal cancer reported a negative impact (**Table 1**).

Partners of patients who underwent external beam therapy (n=50, 65%) reported more negative impact on sexuality and intimacy in comparison with partners of patients without external beam therapy (n=26, 26%; $p<0.01$). Hormonal therapy was also associated with a negative impact on partners' sexuality and intimacy (hormonal therapy vs no hormonal therapy; n=38, 70% vs n=86, 51%, $p=0.01$). Age, stage of disease, surgery, chemotherapy and internal beam therapy were not significantly associated with greater negative impact on sexuality and intimacy (p-value ranges from 0.06 to 0.7; **Table 1**).

Characteristics associated with need for information

A majority of the respondents (n=137, 59.6%) reported a need for information (**Table 1**). Respondents who reported a negative impact of cancer on their sexuality and intimacy were more in need of information ($p<0.01$). Age, gender, stage of disease, time from diagnosis and type of treatment were not related to a higher need for information (p-value ranges from 0.4 to 0.7; **Table 1).**

Table 1:
Characteristics of the respondents
Self-reported negative impact of the respondents
Self-reported need for information of the respondents

	Participants n (%)	Negative impact n(%)	Need for information n(%)
All	230 (100)	127 (55.9)	137 (59.6)
Gender			
Female	129 (56.1)	82 (65.1)	78 (60.5)
Male	100 (43.4)	45 (45.0)	58 (58.0)
Missing	1 (0.4)		
Age (years)	Median 64 (20-84)		
< 50	24 (10.5)	7 (29.2)	12 (50.0)
50 – 70	153 (66.5)	93 (61.6)	98 (64.1)
> 70	53 (23.0)	27 (51.9)	27 (50.9)
Cancer type*			
Prostate	66 (28.7)	47 (74.6)	45 (68.2)
Breast	56 (24.3)	32 (57.1)	40 (71.4)
Gastro-intestinal	46 (20.0)	29 (56.5)	28 (60.9)
Other	34 (14.8)	18 (52.9)	17 (50.0)
Unknown	36 (15.7)	8 (22.2)	14 (38.9)
Time since diagnosis			
≤ 2 year	51 (27.9)	35 (71.4)	36 (70.0)
3-5 year	72 (39.3)	46 (64.8)	48 (66.7)
6-10 year	39 (21.3)	21 (53.8)	21 (53.8)
> 10 year	21 (11.5)	17 (53.8)	18 (56.3)
Stage of cancer			
Limited	151 (79.0)	59 (39.9)	97 (64.2)
Metastatic	38 (21.0)	10 (26.3)	24 (63.2)
Treatment*			
Surgery	157 (68.3)	93 (60.4)	98 (62.4)
External beam therapy	91 (39.6)	65 (71.4)	58 (63.7)
Chemotherapy	80 (34.8)	49 (61.3)	52 (65.0)
Hormonal therapy	54 (23.5)	38 (70.3)	36 (66.7)
Internal beam therapy	20 (8.7)	14 (70)	14 (70)

* Multiple answers possible

Preferences for communication
When facing sexuality and intimacy problems, most respondents (n=88, 69.3%) discussed the problems with their partner. A minority (n=12, 9.4%) talked to their healthcare provider about the problems or searched for information themselves (n=15, 11.8%).

Participants, who stated to have a need for information, were asked about their ideas to enhance communication with the healthcare provider about sexuality and intimacy. The majority of the partners (71.5%, n=98) suggest that a healthcare professional should provide information regarding sexuality and intimacy systematically. Half of the respondents (n=72, 52.6%) suggested that the healthcare professionals should be actively involved them in discussing sexuality and intimacy. Less partners were interested in an accessible referral to a sexologist to discuss sexuality and intimacy issues due to cancer (n=44, 32.1%).

Next, participants were requested what kind of information would be helpful for them. **Table 2** displays the need for kind of information per gender, age and cancer type. Slightly more than half of all responding partners preferred practical advice regarding sexuality and intimacy (n=76, 55%). Experiences from others (n=64, 46.7%), practical information (etiology, prevalence) (n=60, 43.8%) and information specific for partners (n=60, 43.8%) were next most mentioned. Significantly more men than women were in need of practical advice and information for partners (p=0.04, p=0.03).

Table 2: Kind of information required*

	Practical advice n(%)	Experiences from others n(%)	Practical information n(%)	Information for partners n(%)	None n(%)
Gender					
Female	41 (31.8)	35 (27.1)	31 (24.0)	28 (21.7)	51 (39.5)
Male	35 (35.0)	29 (29.0)	28 (28.0)	32 (32.0)	42 (42.0)
Age					
< 50 years	6 (25.0)	7 (29.2)	6 (25.0)	6 (25.0)	12 (50.0)
50 – 70 years	58 (37.9)	47 (30.7)	41 (26.8)	44 (28.8)	55 (35.9)
> 70 years	12 (22.6)	10 (18.9)	13 (24.5)	10 (18.9)	26 (49.1)
Cancer type					
Breast	25 (55.3)	21 (62.5)	22 (39.3)	24 (42.9)	16 (28.6)
Prostate	23 (66.2)	41 (64.6)	15 (21.5)	19 (29.2)	21 (31.8)
Gastro-intestinal	16 (34.8)	12 (26.1)	12 (26.1)	6 (13.0)	18 (39.1)

* answers to the question “What kind of information regarding intimacy and sexuality do you prefer?”; multiple answers possible

Discussion

This study supports previous research that highlights the need for adequate information regarding sexuality and intimacy for partners of patients with cancer. More than half of the respondents stated that cancer had negatively affect their sexuality and intimacy. Female gender, external beam therapy and hormonal therapy were associated with a higher negative impact. Except a self-reported negative impact of cancer, no characteristics were determinants for a higher need for sexuality related information. Partners prefer to receive information from a healthcare professional and were most interested in information consisting of practical advice and experiences from others.

Younger age and male gender were identified to be related to a higher need of information regarding sexuality and intimacy in patients with cancer (9, 21, 22). In our study, age and gender were not associated with the need for information regarding sexuality and intimacy. Also type of partners' treatment was not related to a higher need of information. This finding suggests that the need of information of the respondents is independent of characteristics (age, gender, treatment) of their partners with cancer. Therefore, it might be difficult to identify partners have a higher need for information. Both partners of a person with reproductive cancer and nonreproductive cancer are known to experience an impact on sexuality (5). This highlight the need to acknowledge sexual concerns of all partners of a someone with cancer. Moreover, partners of patients with cancer may experience feelings of shame and guilt regarding their sexual desires and they feel sexual needs are inappropriate (5). Hence, they might be less likely to report a need for support and information regarding sexuality and intimacy. It can be argued that information should be easily accessible and actively provided to partners, as they indicate in this survey. As the need for information is obvious both for partners and cancer patients, this aspect of treatment seems to be neglected in daily practice.

Current literature revealed that partners are not satisfied with the information and support regarding sexuality and intimacy (9). Our findings suggest that partners of patients with cancer are in need of practical advice regarding sexuality and intimacy and experiences from others. Suitable information with respect to sexuality and intimacy for partners can be helpful to prepare partners for sexual side effects and create realistic expectations about sexual function after cancer (12). Lack of knowledge regarding sexual side effects can lead to unmet sexual needs, which can negatively influence quality of life and may result in lower levels of relationship satisfaction (23-25). Moreover, knowledge on sexual side effects will foster communication about sexuality and intimacy within medical practice. Open communication about sexuality and intimacy may results in better coping with sexual problems (24, 26, 27).

Patients with cancer reported to prefer their partners to be involved in communication regarding sexuality and intimacy and sexual recovery with a healthcare provider, and so do their partners (12).In accordance with our study, in current medical practice, a discussion about sexuality and intimacy with a healthcare provider does not take place for most cancer patients and partners due to mismatched expectations or barriers by healthcare professionals or patients to bring up the subject (4, 5, 9, 18, 28). Therefore, it is recommended that information regarding sexuality and intimacy is also widely available independent of healthcare providers.

Strength of this study is a larger sample size than existing studies regarding our topic (5, 9, 11, 20, 21). However, a sample size calculation could not calculated beforehand. More research among partners is needed in order to strengthen our findings. Another strength is the participation of partners from patients with diverse cancer types. A number of limitations need to be considered. First, a non-validated questionnaire was used. There was no questions on the duration of the relationship, ethnical and religious aspects, which might influence the negative impact on sexuality and the need of information. Both may be incorporated in future research.

The response rate might have caused nonresponse bias. Our response rate is slightly higher in comparison with surveys about sexuality among partners of patients with cancer (9). Besides, selection bias might have occurred. Not all cancer types were represented in this study. The reported negative effect of cancer on sexuality and intimacy was lower in our study (55.9%) than reported in literature (69-78%) (5, 6). This may be due to the lack of partners of patients with gynecologic cancer, who are known to report a high negative impact on sexuality and intimacy (7, 29). However, there was a good spread across gender and treatment modalities. Moreover, the sample size was larger in contrast with previous studies investigating cancer and sexuality and intimacy among partners (5-9).

Besides, recall bias might have occurred. Sexuality and intimacy problems are known to be a late effect of cancer and are likely to continue during long-term survival (1). According to our survey, partners of cancer patients are mostly affected in the first five years after diagnosis. Following on from this, the need for information was also highest in the first five years. However, some partners describe sexuality and intimacy as a nonissue during treatment (7). In time, people want life after treatment to return to as normal as possible again and may have more attention for sexuality and intimacy. They need to find a new approach to sexuality and intimacy. During this phase, information regarding sexuality and intimacy might be also important. This supports our findings that half of the partners stated a need for information more than ten years after diagnosis.

Further research could focus on the role of different psychological factors in information need regarding sexuality and intimacy in partners. Moreover, future research could include a longitudinal prospective study to evaluate information for partners per type of cancer. The results of this survey were used for the development of a website with information for partners of cancer patients about cancer and sexuality and intimacy (www.kankerenseks.nl).

Conclusion

In conclusion, our findings underscore that information regarding sexuality and intimacy for partners of patients with cancer is important with the limited majority of partners. Partners prefer to receive information regarding sexuality and intimacy from a healthcare provider as routine care. Information should include practical advice and experiences from others. Suitable information, adjusted to partners social and cognitive condition, may support partners and patients to cope with changed sexuality and intimacy after cancer and is important to be included in supportive cancer care.

REFERENCES

1. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9.
2. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. Journal of cancer survivorship : research and practice. 2016;10(3):600-9.
3. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.
4. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94.
5. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer nursing. 2009;32(4):271-80.
6. Lehto US, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. European journal of cancer care. 2018;27(1).
7. Oldertroen Solli K, de Boer M, Nyheim Solbraekke K, Thoresen L. Male partners' experiences of caregiving for women with cervical cancer-a qualitative study. Journal of clinical nursing. 2019;28(5-6):987-96.
8. Miaja M, Platas A, Martinez-Cannon BA. Psychological Impact of Alterations in Sexuality, Fertility, and Body Image in Young Breast Cancer Patients and Their Partners. Revista de investigacion clinica; organo del Hospital de Enfermedades de la Nutricion. 2017;69(4):204-9.
9. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.
10. Garos S, Kluck A, Aronoff D. Prostate cancer patients and their partners: differences in satisfaction indices and psychological variables. The journal of sexual medicine. 2007;4(5):1394-403.
11. Gilbert E, Ussher JM, Hawkins Y. Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. Health (London, England : 1997). 2009;13(5):523-41.
12. Mehta A, Pollack CE, Gillespie TW, Duby A, Carter C, Thelen-Perry S, et al. What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study. Sexual medicine. 2019;7(2):184-91.
13. Rottmann N, Gilsa Hansen D, dePont Christensen R, Hagedoorn M, Frisch M, Nicolaisen A, et al. Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. Acta oncologica (Stockholm, Sweden). 2017:1-8.
14. Kroenke CH, Michael YL, Poole EM, Kwan ML, Nechuta S, Leas E, et al. Postdiagnosis social networks and breast cancer mortality in the After Breast Cancer Pooling Project. Cancer. 2017;123(7):1228-37.
15. Hautamaki-Lamminen K, Lipiainen L, Beaver K, Lehto J, Kellokumpu-Lehtinen PL. Identifying cancer patients with greater need for information about sexual issues. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2013;17(1):9-15.
16. Vermeer WM, Bakker RM, Kenter GG, Stiggelbout AM, Ter Kuile MM. Cervical cancer survivors' and partners' experiences with sexual dysfunction and psychosexual support. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2016;24(4):1679-87.
17. Albers LF, van Belzen MA, van Batenburg C, Engelen V, Putter H, Pelger RCM, et al. Discussing sexuality in cancer care: towards personalized information for cancer patients and survivors. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2020.

18. Krouwel EM, Albers LF, Nicolai MPJ, Putter H, Osanto S, Pelger RCM, et al. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
19. Nicolai MP, van Bavel J, Somsen GA, de Grooth GJ, Tulevski, II, Lorsheyd A, et al. Erectile dysfunction in the cardiology practice-a patients' perspective. American heart journal. 2014;167(2):178-85.
20. Grondhuis Palacios LA, Krouwel EM, den Oudsten BL, den Ouden MEM, Kloens GJ, van Duijn G, et al. Suitable sexual health care according to men with prostate cancer and their partners. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018;26(12):4169-76.
21. Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. Cancer nursing. 2002;25(1):42-9.
22. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
23. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(2):135-45.
24. Park BW, Hwang SY. Unmet Needs and Their Relationship with Quality of Life among Women with Recurrent Breast Cancer. J Breast Cancer. 2012;15(4):454-61.
25. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405.
26. Geue K, Schmidt R, Sender A, Sauter S, Friedrich M. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. Psychooncology. 2015;24(11):1368-76.
27. Robinson L, Miedema B, Easley J. Young adult cancer survivors and the challenges of intimacy. J Psychosoc Oncol. 2014;32(4):447-62.
28. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
29. Lopez V, Copp G, Molassiotis A. Male caregivers of patients with breast and gynecologic cancer: experiences from caring for their spouses and partners. Cancer nursing. 2012;35(6):402-10.

Chapter 5: Sexual health needs: how do breast cancer patients and their partners want information?

Albers LF, van Ek GF, Krouwel EM, Oosterkamp-Borgelink CM, Liefers GJ, Den Ouden MEM, Den Oudsten BL, Krol-Warmerdam EEM, Guicherit OR, Linthorst-Niers E, Putter H, Pelger RCM, Elzevier HW

Journal of Sex & Marital Therapy. 2019 Nov 25:1-22

Introduction

Breast cancer is the most common type of cancer among women (1, 2). Since the number of breast cancer survivors has increased over the past years due to more effective treatment there is more attention for improving patient's wellbeing and quality of life (3). Sexual functioning is considered to be an important aspect of quality of life and is included in the latest set of value-based patient-centred outcomes for women with breast cancer(4). Sexual problems are common after breast cancer treatment with an estimated prevalence up to 85% (5-7). Breast cancer treatment, including surgical treatment, radiotherapy, chemotherapy, hormonal therapy and immunotherapy can cause physical sexual problems, such as problems with vaginal lubrication, decreased nipple sensation and reduced desire due to treatment-induced menopause (8-12). Besides, psychological sexual problems, e.g. disturbance in body image and physical unattractiveness could affect sexual function regardless of treatment (13-17). The negative effect of sexual problems on patients' wellbeing has been well studied (5, 9, 12, 13, 18, 19). Moreover, sexual problems affect not only patients, their partners are likely to suffer as well (20-23). As a consequence, relationships and sexuality may change(21, 24). Partners do experience these changes as a struggle(22, 25-27). Attention for patient-partner relationship is important since being in an intimate relationship with affectionate behaviour and emotional closeness is associated with better (psychosocial) outcomes and adaptation to disease in both cancer patients and partners. (28-31). Adequate information and support regarding intimacy and sexuality can reduce distress in patient and partner(11, 32).

Despite the growing literature on the importance of information about sexuality and patients' preferences about its communication, several studies identified that health care providers in the field of oncology do not routinely provide information on sexuality nor discuss this subject with their patients and partners(27, 33-43). As a result, patients and partners receive little support for sexual health issues(24).

Previous research showed that patients and partners do consider information about sexuality and relationships as important(1, 44-46) and they prefer to receive oral as well as written information regarding sexuality(6). Existing literature describes preferences of breast cancer patients about oral patient-provider communication regarding sexuality. Patients prefer an open discussion about sexuality with a health care provider where the provider initiated sexuality during a conversation, normalize sexuality related issues and acknowledge the magnitude of the subject(32, 41, 47). Less is known about the breast cancer patients' and survivors' preferred modality of written information provision(6). Moreover, little is known on the preferred type of health care provider to discuss sexuality with and suitable timing for information. Besides, partners' preferences for communication about sexuality may differ from patients' preferences and their view is less described in previous literature(41). It is unknown if preferences of partners differ from patients preferences.

Hence, we aimed to evaluate patients' and partners' preferences of written information regarding sexuality, their most preferred health care professional to discuss sexuality with and what timing is considered to be most suitable moment for discussing sexuality.

Methods

This multicentre study was conducted between March and December 2017. Data for this cross-sectional study were collected using a questionnaire. Female patients who were treated for non-invasive or invasive breast cancer between January 2015 and December 2016 at University Cancer Center Leiden – The Hague and the Groene Hart Hospital (Gouda) in the Netherlands were selected. Exclusion criteria were patients under the age of 18, patients with a benign breast tumour and patients who moved abroad. No selection criteria according to maximum age of the patients was made.

Invitation letters explaining the purpose of the study including an informed consent form were sent by post to patients. All patients also received an extra invitation for a partner. After informed consent was obtained, the questionnaires were sent by post or email, according to the preference of the respondent. If the patient declined participation, the partner could still be included and vice versa.

According to the advice of the Medical Ethics Committee of the Leiden University Medical Center, the information letters were only sent once; no further attempt was made if the permission form was not returned.

Questionnaire

The questionnaires were developed by the authors and were based on the study aim and review of literature. Structure and design of these questionnaires were derived from questionnaires used in previous studies performed by our research institute to evaluate sexual health care (34, 35, 48-50). The questionnaire developed for breast cancer patients consisted of 57 items assessing topics such as demographic factors, sexual function before and after diagnosis, their experiences and satisfaction with current sexual health care and their preferences regarding sexual health care (Appendix 5). A comparable questionnaire was designed for the partners of the breast cancer patients. It consisted 37 items, assessing demographic factors, their experiences with sexuality during the treatment process of their partner and their preferences on sexual health care (Appendix 6).

The questionnaires were pilot tested by a specialised test panel of the Dutch Breast Cancer Society (Borstkankervereniging Nederland). The questionnaire for partners was pilot tested by partners of the test panel. The questionnaire was adjusted according to their comments; for example linguistic adjustments were made, open-ended options as well as questions on changes of body image were added.

Privacy
All data containing personal information of participants were stored securely and only authorized members of the research team had access to the data. After informed consent was obtained, the participants received an identification code to ensure privacy.

Statistical analysis
All data were analysed using IBM SPSS statistics 23 (SPSS Inc., Armonk, NY: IBM Corp). Demographic information and responses to the survey were analysed using descriptive statistics. Difference in age between respondents and non-respondents was calculated using the independent sample T-test. Bi- and multivariate associations were calculated using the Pearson's chi-square test and Fishers's exact test. In table 2 oncologist, surgeon, radiotherapist, plastic surgeon were merged to "physician" since some patients might not have consulted each one individually. Outcomes were considered statistically significant if the two-sides P- values were <0.05 (two-sided).

Ethics
The research protocol was approved by the Medical Ethics Committee of the Leiden University Medical Center and the scientific office of Haaglanden Medical Center and Groene Hart Hospital (P16.279). Approval was needed since the questionnaires consisted sensitive questions.

Results

Sample
In total, 1098 breast cancer patients were invited to participate in the study, 208 agreed to participate (19%). The remaining group did not respond. Thirty-five women who gave their consent, did not return the questionnaire. Subsequently, a total of 173 patient questionnaires and 76 partner questionnaires were analysed.

Demographic and clinical characteristics
The responding patients had a mean age of 60.1 years (SD: 11 years, range 29-91 years). No significant difference in age was found between responders and non-responders (mean difference -0.5; 95% CI -2.4, 1.4; p=0.6). Of the respondents, 106 women (62.4%) had local breast cancer. The majority of the women underwent breast conserving surgery (BCS; 66.5%) in combination with external radiotherapy (54.9%). In the group of partners, the median age was 61 year (range 33-79). The majority was male (n=69, 93.3%). All characteristics of the respondents are summarized in **Table 1**.

Table 1: Baseline characteristics of the respondents

	Patients (n=173) n (%)	Partners (n=76) n (%)
Age (years)	Mean 60.1 (SD 11)	Median 61.00 (range 33-79)
Gender		
Female	173 (100)	5 (6.8)
Male	0 (0)	67 (93.2)
Relationship (median in years)	28.4 (range 1 – 55)	
Marital status		
Single	27 (15.6)	
In a relationship	128 (74.0)	
Widow	18 (10.4)	
Education*		
Non or elementary school	5 (2.9)	2 (2.6)
Middle-level applied	46 (27.1)	9 (11.8)
Intermediate vocational	25 (14.7)	18 (23.7)
High school	28 (16.5)	7 (9.2)
Bachelor degree or higher	66 (38.8)	40 (52.6)
Work*		
Yes	71 (42.5)	44 (57.9)
No, jobseeker	6 (3.6)	2 (2.6)
No, not able due to illness	15 (9.0)	0 (0)
No, retiree	64 (38.3)	27 (35.5)
Other	11 (6.6)	3 (3.9)
Stage*		
DCIS	28 (16.5)	
Local breast cancer	106 (62.4)	
Metastases in the axilla	33 (19.4)	
Metastases elsewhere	3 (1.8)	

Continuation ***Table 1***

Type of surgery	
Non	3 (1.5)
Breast conserving surgery	115 (58.1)
Mastectomy,without reconstruction	24 (12.1)
Mastectomy, with reconstruction	32 (16.2)
Axillary lymph node dissection	24 (12.1)
Additional treatment**	
None	21 (12.1)
Neo-adjuvant chemotherapy	29 (16.8)
Chemotherapy	28 (16.2)
Radiotherapy	95 (54.9)
Intra-operative radiation therapy	21 (12.1)
Hormonal therapy	50 (28.9)
Immunotherapy	16 (9.2)

* n differs because some respondents skipped the question
** n differs due to multiple answers that could be given to this question

Patients' preferences on information regarding sexuality

The majority of respondents (80.4%, n=135) stated to not have received any information about effect of their breast cancer on sexuality. A quarter (24.9%, n=42) reported a need for information regarding sexuality; of them 62.0% (n=26) did not receive any information.
To the assumption that every breast cancer patients should be offered an opportunity to discuss sexuality, 47.6% agreed, 20.0% disagreed and 32.4% answered neutral.

We asked the participants how they would prefer to receive information regarding sexuality. Around half of the responding breast cancer patients (n=84, 48.6%) answered positively to the suggestion of a brochure with information about sexuality. To the suggestion that information was provided via a website, 35.3% (n=61) of the respondents agreed and 27.2% (n=47) preferred a conversation with a health care professional to obtain information regarding sexuality.

To the question which health care provider they would prefer to discuss sexuality with, 51% (n=88) answered positively to the assumption this would be with a nurse practitioner. Sexologist (n=29, 17%) and general practitioner (resp. n=28, 16%) were next most mentioned. Seventeen (n=29) agreed to the suggestion that they do not have a need to have conversation with a health care provided about sexuality. Next, participants' view on most appropriate timing were asked. Half of the patients (n=81, 46.6%) considered during treatment as most suitable moment to discuss sexuality. On the assumption the best moment would be before treatment 32.4% (n=56) agreed and a quarter (n=43, 24,9%) preferred end of treatment. All preferences according all formats of information, preferred health care professionals and timing are displayed in **Table 2.**

Table 2: Patients' and partners' with an information need: preference on format, health care provider and timing for receiving information regarding sexuality

	Patients	Partners	p-value
	n (%)	n (%)	
Format*			
Brochure	84 (68.2)	31 (55.4)	ns
Website	61 (49.6)	26 (46.4)	ns
Consultation with professional	47 (38.2)	26 (46.4)	ns
Via the breast cancer association	32 (26.0)	6 (10.7)	0.02
Via a patient forum	18 (14.6)	6 (10.7)	ns
App	16 (13.0)	7 (12.5)	ns
Group session with a professional	14 (11.4)	4 (7.1)	ns
Via the cancer society	12 (9.8)	5 (8.9)	ns
Via fellow patients	12 (9.8)	6 (10.7)	ns
Health care provider*			
Nurse practitioner	88 (64.2)	40 (65.6)	ns
Physician	39 (22.5)	21 (34.4)	ns
Sexologist	29 (21.1)	9 (14.8)	ns
General practitioner	28 (20.4)	17 (28.9)	ns
Psychologist	20 (14.6)	8 (13.1)	ns
Social worker	10 (7.3)	3 (4.9)	ns
Timing*			
Before treatment	56 (32.4)	38 (50.0)	0.01
During treatment	81 (46.8)	23 (30.3)	0.02
After treatment	43 (24.9)	21 (27.6)	ns

** n differs due to multiple answers that could be given to this question*

If sexuality was discussed by a health care provider, the majority of the patients in a relationship (61.3%, n=68) stated that the presence of their partner as important. The rest (n=43, 38.7%) considered it as not important. Half of the patients (n=54, 48.6%) stated that every partner should be offered an opportunity to discuss sexuality with a health care provider. A third was neutral (n=37) and 18% (n=20) disagreed to this assumption.

Partners
Of all partners, 73.7% (n=56) stated to not have received any information about possible sexuality problems due to cancer. A quarter (n=19) reported a need for information regarding sexuality; half of them (n=9, 47%) received this information. The nurse practitioner was the most preferred health care professional (n=40, 52.6%) to discuss sexuality with. Partners mostly preferred to receive information via a brochure (n=31, 40.8%). In comparison to the responding patients, partners were less likely to gain information via the breast cancer association (p=0.02). Significantly more partners (n=38, 50%) than responding patients (n=56, 32.4%) considered before treatment as best moment to discuss sexuality (p=0.01). More than half of the partners (n=42, 55.3%) stated their involvement during sexual counselling of their partners as important, 42.1% (n=32) left it up to their partners and 2.6% (n=2) considered their presence as not important. To the suggestion that every partner should be offered an opportunity to discuss sexuality with a health care provider, 40% (n=30) agreed, 22.7% (n=17) disagreed and 37.3% (n=28) answered neutral.

Discussion

It is well known that women with breast cancer and their partners frequently experience negative changes in their relationship and sexuality (20-23, 51). Although most patients and partners in our survey did not report a direct need for information regarding sexuality, most valued an opportunity to discuss sexuality. Both patients and partner prefer to receive information via a breast cancer practitioner through a website or brochure. Patients think during treatment is the most suitable timing to discuss sexuality. However, partners would like to discuss sexuality at the beginning of treatment.

In concordance with previous literature, the current study confirms that sexuality is not routinely discussed by health care providers with patients and their partners with most respondents not having received information regarding sexuality(7). However, the reported need for information reported by patients in our study (24.9%) was lower compared to results of two previous studies (60-70%) which investigated information need regarding sexuality in breast cancer patients who were recruited via Breast Cancer Associations(6, 52). The information need in partners in our study was comparable with the need of the responding patients(both 25%). However, partners in our study valued an opportunity to discuss sexuality with a health care provider and wanted to be present when sexuality was discussed with their partners. It is important for health care providers to involve partners as literature reveals that partners who did not receive accurate information are more distressed than partners who felt well informed(53). Moreover, previous literature reported that breast cancer patients do consider information for their partners as very important(6). Partners may not always present when sexuality is discussed during a consultation with a health care provider. Therefore written information about sexuality might be helpful for partners to be informed about possible sexuality issues(53). Patients and partners prefer written information via a brochure or website. Partners were less likely than their patients to obtain their information via the breast cancer association. It can be argued that information should be offered in multiple ways to meet patients' and partners' preferences and reach them as much as possible.

Suitable timing for communication about sexuality is essential. We found a differences in preferences of patients and partners according to most suitable timing to discuss sexuality. However, both patient and partners suggest there should be multiple moments during the treatment trajectory to discuss sexuality. Previous research which investigated the need for information regarding sexuality in breast cancer who were diagnosed 5 years ago stressed the importance of appropriate timing of information;. at start of during beginning of the treatment(52). This is important since patients and partners might underestimate the influence of treatment on sexuality at the start or during treatment (54). Moreover, it is known that patients and partners found it difficult to raise a discussion about sexuality. Lack of communication about the subject may lead to problems with coping and conflicts between couples(23, 55, 56). Discussing sexuality with patient and partner before start of treatment would be helpful to inform them about possible changes in sexuality and to manage expectations. Including sexuality in consultations repeatedly through the treatment process and follow-up is advised since the need for information and support regarding sexuality changes over time(52). The implementation of fixed moments during treatment and follow up to discuss the topic might have added value (54, 57).

In line with the literature, patients and partners, reported to feel most comfortable to discuss sexuality with a nurse practitioner(6, 52). The nurse practitioner plays a coordination role in the treatment process and supports the patients during the whole treatment and follow up. Previous studies reveal that nurses do feel responsible for bringing up sexuality but they encounter several barriers such as lack of time and lack of training (49). Nurse practitioners could assume responsibility within a multidisciplinary team for discussing the subject with the breast cancer patients and partners. For implementation into practice, nurse practitioners should have access to training and (written) information regarding sexuality. It would be useful if written material such as a brochure or website, is easily available to everyone to empower patients and partners themselves. New approaches to enhance sexual care for patients and their partners, such as internet tools and interventions, are promising and interesting for further research (58-60).

Study limitations
To our best knowledge, this is the first study which evaluated the information needs regarding sexuality and relationship of breast cancer patients and partners at the same moment. This paper adds new insights on preferences of partners regarding information about sexuality and explored the differences with the preferences of their partners. A number of limitations needs to be considered. First, we used a non-validated questionnaire, since there are no validated questionnaires available. Second, our response rate was low which might have resulted in bias. Explanations for the response rate are timing of the questionnaire (shortly after diagnosis), the sensitivity of the subject and the fact that no permission was obtained to send a reminder or ask for reasons of refusal. Our findings should be interpreted carefully and may be not generalizable for all breast cancer patients and partners. This is one of the few studies exploring the differences between preferences

of patients and partners with regard to sexuality related information. Therefore, the results of this study might be a starting point for further exploration. Longitudinal studies of interventions based on preferences of patients and partners and studies which measure pre- and post- comfort with sexuality communication after receiving information are needed.

Conclusion

At the moment, sexual health care seems not to be a standard part of breast cancer care in the first two years after breast cancer diagnosis. Most of the respondents, patients and partners, did not report a direct need for information regarding sexual problems during this survey, but value an opportunity to discuss the subject if needed. The most suitable moment for such a consultation was considered to be at the beginning or during, provided by a nurse practitioner, supported by a brochure or website. It is advised to offer an opportunity to discuss sexuality with patients and partners at multiple moments during treatment and follow up.

REFERENCES

1. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.
2. IARCG. Breast Cancer Estimated Incidence, Mortality and Prevalence Worldwide in 2012. http: //globocan.iarc.fr/old/FactSheets/cancers/breast-new.asp. Accessed February 21, 2017.
3. Kool M, van der Sijp JR, Kroep JR, Liefers GJ, Jannink I, Guicherit OR, et al. Importance of patient reported outcome measures versus clinical outcomes for breast cancer patients evaluation on quality of care. Breast (Edinburgh, Scotland). 2016;27:62-8.
4. Ong WL, Schouwenburg MG, van Bommel AC, Stowell C, Allison KH, Benn KE, et al. A Standard Set of Value-Based Patient-Centered Outcomes for Breast Cancer: The International Consortium for Health Outcomes Measurement (ICHOM) Initiative. JAMA oncology. 2016.
5. Panjari M, Bell RJ, Davis SR. Sexual function after breast cancer. The journal of sexual medicine. 2011;8(1):294-302.
6. Ussher JM, Perz J, Gilbert E. Information needs associated with changes to sexual well-being after breast cancer. J Adv Nurs. 2013;69(2):327-37.
7. Chang YC, Chang SR, Chiu SC. Sexual Problems of Patients With Breast Cancer After Treatment: A Systematic Review. Cancer nursing. 2018.
8. Montazeri A, Vahdaninia M, Harirchi I, Ebrahimi M, Khaleghi F, Jarvandi S. Quality of life in patients with breast cancer before and after diagnosis: an eighteen months follow-up study. BMC cancer. 2008;8:330.
9. Raggio GA, Butryn ML, Arigo D, Mikorski R, Palmer SC. Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. Psychology & health. 2014;29(6):632-50.
10. Arraras JI, Manterola A, Asin G, Illarramendi JJ, Cruz Sde L, Ibanez B, et al. Quality of life in elderly patients with localized breast cancer treated with radiotherapy. A prospective study. Breast (Edinburgh, Scotland). 2016;26:46-53.
11. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9.
12. Biglia N, Moggio G, Peano E, Sgandurra P, Ponzone R, Nappi RE, et al. Effects of surgical and adjuvant therapies for breast cancer on sexuality, cognitive functions, and body weight. The journal of sexual medicine. 2010;7(5):1891-900.
13. Boquiren VM, Esplen MJ, Wong J, Toner B, Warner E, Malik N. Sexual functioning in breast cancer survivors experiencing body image disturbance. Psycho-oncology. 2016;25(1):66-76.
14. Figueiredo MI, Cullen J, Hwang YT, Rowland JH, Mandelblatt JS. Breast cancer treatment in older women: does getting what you want improve your long-term body image and mental health? Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2004;22(19):4002-9.
15. Teo I, Reece GP, Christie IC, Guindani M, Markey MK, Heinberg LJ, et al. Body image and quality of life of breast cancer patients: influence of timing and stage of breast reconstruction. Psycho-oncology. 2016;25(9):1106-12.
16. Teo I, Novy DM, Chang DW, Cox MG, Fingeret MC. Examining pain, body image, and depressive symptoms in patients with lymphedema secondary to breast cancer. Psycho-oncology. 2015;24(11):1377-83.
17. Radina ME, Fu MR, Horstman L, Kang Y. Breast cancer-related lymphedema and sexual experiences: a mixed-method comparison study. Psycho-oncology. 2015;24(12):1655-62.
18. Badhwar G, Bhama S, Vakhariya C, Goodman JR. Impact of breast cancer diagnosis and treatment on sexual dysfunction. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2014;32(26_suppl):125.
19. Dizon DS, Suzin D, McIlvenna S. Sexual health as a survivorship issue for female cancer survivors. The oncologist. 2014;19(2):202-10.

20. Nakaya N, Saito-Nakaya K, Bidstrup PE, Dalton SO, Frederiksen K, Steding-Jessen M, et al. Increased risk of severe depression in male partners of women with breast cancer. Cancer. 2010;116(23):5527-34.

21. Pluchino N, Wenger JM, Petignat P, Tal R, Bolmont M, Taylor HS, et al. Sexual function in endometriosis patients and their partners: effect of the disease and consequences of treatment. Human reproduction update. 2016;22(6):762-74.

22. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer nursing. 2009;32(4):271-80.

23. Rowland E, Metcalfe A. A systematic review of men's experiences of their partner's mastectomy: coping with altered bodies. Psycho-oncology. 2014;23(9):963-74.

24. Keesing S, Rosenwax L, McNamara B. A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. BMC women's health. 2016;16:57.

25. de Groot JM, Mah K, Fyles A, Winton S, Greenwood S, Depetrillo AD, et al. The psychosocial impact of cervical cancer among affected women and their partners. International journal of gynecological cancer : official journal of the International Gynecological Cancer Society. 2005;15(5):918-25.

26. Albaugh JA, Sufrin N, Lapin BR, Petkewicz J, Tenfelde S. Life after prostate cancer treatment: a mixed methods study of the experiences of men with sexual dysfunction and their partners. BMC urology. 2017;17(1):45.

27. Miaja M, Platas A, Martinez-Cannon BA. Psychological Impact of Alterations in Sexuality, Fertility, and Body Image in Young Breast Cancer Patients and Their Partners. Revista de investigacion clinica; organo del Hospital de Enfermedades de la Nutricion. 2017;69(4):204-9.

28. Rottmann N, Gilsa Hansen D, dePont Christensen R, Hagedoorn M, Frisch M, Nicolaisen A, et al. Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. Acta oncologica (Stockholm, Sweden). 2017:1-8.

29. Kroenke CH, Michael YL, Poole EM, Kwan ML, Nechuta S, Leas E, et al. Postdiagnosis social networks and breast cancer mortality in the After Breast Cancer Pooling Project. Cancer. 2017;123(7):1228-37.

30. Pistrang N, Barker C. The partner relationship in psychological response to breast cancer. Social science & medicine (1982). 1995;40(6):789-97.

31. Zimmermann T. Intimate Relationships Affected by Breast Cancer: Interventions for Couples. Breast care (Basel, Switzerland). 2015;10(2):102-8.

32. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.

33. Faghani S, Ghaffari F. Effects of Sexual Rehabilitation Using the PLISSIT Model on Quality of Sexual Life and Sexual Functioning in Post-Mastectomy Breast Cancer Survivors. Asian Pacific journal of cancer prevention : APJCP. 2016;17(11):4845-51.

34. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.

35. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.

36. Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. British journal of cancer. 2003;88(5):666-71.

37. Wiggins DL, Wood R, Granai CO, Dizon DS. Sex, intimacy, and the gynecologic oncologists: survey results of the New England Association of Gynecologic Oncologists (NEAGO). Journal of psychosocial oncology. 2007;25(4):61-70.

38. Wang F, Chen F, Huo X, Xu R, Wu L, Wang J, et al. A neglected issue on sexual well-being following breast cancer diagnosis and treatment among Chinese women. PloS one. 2013;8(9):e74473.

39. Reese JB, Sorice K, Lepore SJ, Daly MB, Tulsky JA, Beach MC. Patient-clinician communication about sexual health in breast cancer: A mixed-methods analysis of clinic dialogue. Patient education and counseling. 2019;102(3):436-42.

40. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.

41. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.

42. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.

43. Butcher J DC, Atkinson A, Clayton A, Couzins-Scott A. Sex and Cancer: opening difficult therapeutic conversations and challenging assumptions using Design Activism-language outside the comfort zone. Sexual and Relationship Therapy. 2016;31(4):493-509.

44. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.

45. Gilbert E, Ussher JM, Hawkins Y. Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. Health (London, England : 1997). 2009;13(5):523-41.

46. McClelland S. “I wish I'd known”: patients' suggestions for supporting sexual quality of life after diagnosis with metastatic breast cancer. Sexual and Relationship Therapy. 2016;31(4):414-31.

47. Reese JB, Beach MC, Smith KC, Bantug ET, Casale KE, Porter LS, et al. Effective patient-provider communication about sexual concerns in breast cancer: a qualitative study. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2017;25(10):3199-207.

48. van Ek GF, Krouwel EM, Nicolai MP, Bouwsma H, Ringers J, Putter H, et al. Discussing Sexual Dysfunction with Chronic Kidney Disease Patients: Practice Patterns in the Office of the Nephrologist. The journal of sexual medicine. 2015;12(12):2350-63.

49. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.

50. Nicolai MP, Liem SS, Both S, Pelger RC, Putter H, Schalij MJ, et al. What do cardiologists know about the effects of cardiovascular agents on sexual function? A survey among Dutch cardiologists. Part I. Netherlands heart journal : monthly journal of the Netherlands Society of Cardiology and the Netherlands Heart Foundation. 2013;21(12):540-4.

51. Nasiri A, Taleghani F, Irajpour A. Men's sexual issues after breast cancer in their wives: a qualitative study. Cancer nursing. 2012;35(3):236-44.

52. Den Ouden MEM, Pelgrum-Keurhorst MN, Uitdehaag MJ, De Vocht HM. Intimacy and sexuality in women with breast cancer: professional guidance needed. Breast cancer (Tokyo, Japan). 2018.

53. Mireskandari S, Meiser B, Sherman K, Warner BJ, Andrews L, Tucker KM. Evaluation of the needs and concerns of partners of women at high risk of developing breast/ovarian cancer. Psycho-oncology. 2006;15(2):96-108.

54. Dikmans REG, van de Grift TC, Bouman MB, Pusic AL, Mullender MG. Sexuality, a topic that surgeons should discuss with women before risk-reducing mastectomy and breast reconstruction. Breast. 2018;43:120-2.

55. Sandham C, Harcourt D. Partner experiences of breast reconstruction post mastectomy. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2007;11(1):66-73.

56. Holmberg SK, Scott LL, Alexy W, Fife BL. Relationship issues of women with breast cancer. Cancer nursing. 2001;24(1):53-60.

57. Stabile C, Goldfarb S, Baser RE, Goldfrank DJ, Abu-Rustum NR, Barakat RR, et al. Sexual health needs and educational intervention preferences for women with cancer. Breast cancer research and treatment. 2017.

58. Hummel SB, van Lankveld J, Oldenburg HSA, Hahn DEE, Kieffer JM, Gerritsma MA, et al. Efficacy of Internet-Based Cognitive Behavioral Therapy in Improving Sexual Functioning of Breast Cancer Survivors: Results of a Randomized Controlled Trial. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2017;35(12):1328-40.

59. Jones LM, McCabe MP. The effectiveness of an Internet-based psychological treatment program for female sexual dysfunction. The journal of sexual medicine. 2011;8(10):2781-92.

60. Hummel SB, van Lankveld J, Oldenburg HSA, Hahn DEE, Kieffer JM, Gerritsma MA, et al. Sexual Functioning and Relationship Satisfaction of Partners of Breast Cancer Survivors Who Receive Internet-Based Sex Therapy. Journal of sex & marital therapy. 2019;45(2):91-10

PART III

THE PATIENT AND THEIR HEALTHCARE PROFESSIONALS

Chapter 6: Discussing sexual health in the medical oncologist's practice: exploring current practice and challenges

Krouwel EM[1], Albers LF[1], Nicolai MPJ, Putter H, Osanto S, Pelger RCM, Elzevier HW

[1]Both authors contributed equally to this manuscript

Journal of Cancer Education. 2020 Dec;35(6):1072-1088

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 optimize 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 30-60 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 (Appendix 7). 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 were 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, lay-out 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 the 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**.

Table 1: Participant characteristics

Oncologists (n=120)	
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)
Gender	**n (%)**
Male	56 (46.7)
Female	63 (52.5)
Unknown	1 (0.8)
Function	
Oncologist	101 (84.2)
Oncology resident	19 (15.8)
Area of expertise*	
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)

Continuation ***Table 1***

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)
Type of practice	
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)
Oncology experience	
< 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)

* Most respondents reported multiple areas of expertise

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.

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 percent (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 **Figure 1**.

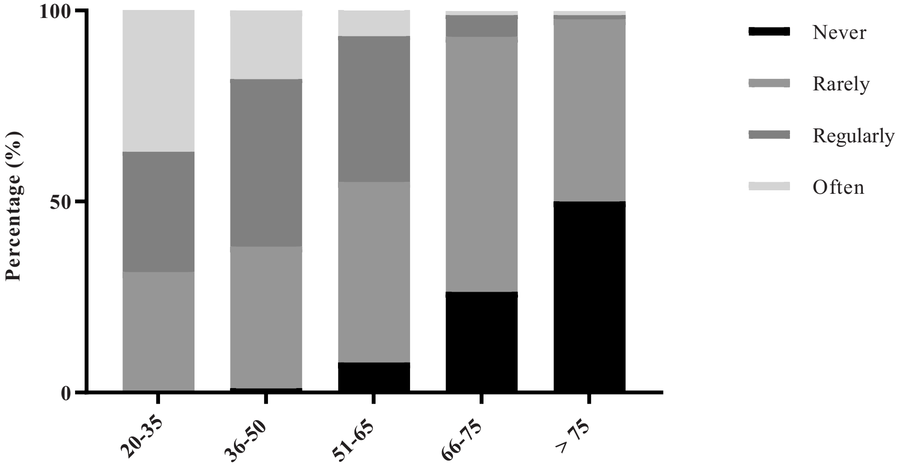


Figure 1: How often do you discuss sexuality within the following age groups (years)?

Table 2: Discussing sexual function in daily practice

	Total respondents	Never/rarely n(%)	In fewer than half of the cases n (%)	In half of the cases n (%)	In more than half of the cases n (%)	Often/always n (%)
How often do you discuss sexual function with your patients?	118	43 (36.1)	54 (45.5)	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? During follow-up, how often do you discuss sexual health with patients?	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

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.

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 (≤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 3: Responsibility for addressing sexual health according to the oncologists

Who is responsible for addressing sexual function? (multiple answers possible)	n (%)
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)

Table 4: list of boundaries for discussing sexual function

Reasons for avoiding discussion of sexual health	Total respondents*	Agree n(%)	Partly agree/disagree n(%)	Disagree n(%)
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)	27 (23.9)
Patient is too ill	114	51 (44.6)	35 (30.7)	28 (24.6)
No angle or 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 does not 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	113	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 to discuss sexual health	102	22 (19.7)	34 (30.4)	46 (50)
Sexuality is a private matter	113	22 (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)
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 is 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 a 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, 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 of 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 minutes) 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 two-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 a 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 specialization 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 specialization 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 specialization.

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.

REFERENCES

1. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]. 2014;12(1):41-53.
2. Kennedy V, Abramsohn E, Makelarski J, Barber R, Wroblewski K, Tenney M, et al. Can you ask? We just did! Assessing sexual function and concerns in patients presenting for initial gynecologic oncology consultation. Gynecologic oncology. 2015;137(1):119-24.
3. Martinez AM SJ, Ressle IB, Ayensu-Coker L, Thomas MA, Lindheim SR. Sexual satisfaction is reduced in the female patient and sexually intimate partners following cancer therapy Advances in Sexual Medicine. 2014;4:65-70.
4. Incrocci L, Jensen PT. Pelvic radiotherapy and sexual function in men and women. The journal of sexual medicine. 2013;10 Suppl 1:53-64.
5. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. Journal of cancer survivorship : research and practice. 2016;10(3):600-9.
6. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9.
7. Scanlon M, Blaes A, Geller M, Majhail NS, Lindgren B, Haddad T. Patient Satisfaction with Physician Discussions of Treatment Impact on Fertility, Menopause and Sexual Health among Pre-menopausal Women with Cancer. Journal of Cancer. 2012;3:217-25.
8. Condorelli M, Lambertini M, Del Mastro L, Boccardo F, Demeestere I, Bober SL. Fertility, sexuality and cancer in young adult women. Current opinion in oncology. 2019.
9. Twitchell DK, Wittmann DA, Hotaling JM, Pastuszak AW. Psychological Impacts of Male Sexual Dysfunction in Pelvic Cancer Survivorship. Sexual medicine reviews. 2019.
10. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.
11. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.

12. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
13. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
14. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94.
15. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.
16. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. Social science & medicine (1982). 2007;64(8):1704-18.
17. Crowley SA, Foley SM, Wittmann D, Jagielski CH, Dunn RL, Clark PM, et al. Sexual Health Concerns Among Cancer Survivors: Testing a Novel Information-Need Measure Among Breast and Prostate Cancer Patients. Journal of cancer education : the official journal of the American Association for Cancer Education. 2016;31(3):588-94.
18. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical

journal. 2011;4(11):610-9.
19. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.
20. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
21. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.

22. Hohwü L, Lyshol H, Gissler M, Jonsson SH, Petzold M, Obel C. Web-based versus traditional paper questionnaires: a mixed-mode survey with a Nordic perspective. Journal of medical Internet research. 2013;15(8):e173-e.
23. Zuidgeest M, Hendriks M, Koopman L, Spreeuwenberg P, Rademakers J. A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care. Journal of medical Internet research. 2011;13(3):e68.
24. Kongsved SM, Basnov M, Holm-Christensen K, Hjollund NH. Response rate and completeness of questionnaires: a randomized study of Internet versus paper-and-pencil versions. Journal of medical Internet research. 2007;9(3):e25.
25. Kwak N, Radler B. A Comparison between Mail and Web Surveys: Response Pattern, Respondent Profile, and Data Quality2002. 257-73 p.
26. Hendriks AC, Vries dMC. Recht op seksuele gezondheid en de rol van de arts. Nederlands Tijdschrift voor Geneeskunde. 2018;2018(162).
27. Storm C, Casillas J, Grunwald H, Howard DS, McNiff K, Neuss MM. Informed Consent for Chemotherapy: ASCO Member Resources. Journal of oncology practice. 2008;4(6):289-95.
28. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World journal of urology. 2006;24(4):423-8.
29. Wang K, Ariello K, Choi M, Turner A, Wan BA, Yee C, et al. Sexual healthcare for cancer patients receiving palliative care: a narrative review. Annals of palliative medicine. 2018;7(2):256-64.
30. Wang LY, Pierdomenico A, Lefkowitz A, Brandt R. Female Sexual Health Training for Oncology Providers: New Applications. Sexual medicine. 2015;3(3):189-97.
31. Jonsdottir JI, Zoega S, Saevarsdottir T, Sverrisdottir A, Thorsdottir T, Einarsson GV, et al. Changes in attitudes, practices and barriers among oncology health care professionals regarding sexual health care: Outcomes from a 2-year educational intervention at a University Hospital. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2016;21:24-30.
32. Hartmann U, Burkart M. Erectile dysfunctions in patient-physician communication: optimized strategies for addressing sexual issues and the benefit of using a patient questionnaire. The journal of sexual medicine. 2007;4(1):38-46.

Chapter 7: Exploring communication about intimacy and sexuality: what are the preferences of adolescents and young adults with cancer and their healthcare professionals?

Albers LF, Haj Mohammad SF, Husson O, Putter H, Pelger RCM, Elzevier HW, Manten-Horst E

Journal of Adolescent and Young Adult Oncology. 2020 Apr;9(2):222-238

Introduction

Psychosexual formation and evolvement of romantic relationships are fundamental developmental milestones of adolescents and young adults (AYA) in normal health(1, 2). In case malignancies occur during this phase of life, cancer can interfere with normal sexual development(3-7).

Cancer treatment has multiple physical side effects which may have an impact on sexuality. Chemotherapy and pelvic radiotherapy, for example, are known to cause problems with lubrication, vaginal atrophy in women and erectile dysfunction in men(5, 8-10). Surgery could cause permanent body changes, with issues with body image and sexual desire as result (11, 12). General treatment complications as pain, fatigue and nausea hinder sexual activity as well (13). Besides, psychological effects of having cancer, like low self-esteem, poorer mental health and body image concerns are associated with a negative impact on sexuality (5). Psychological aspects are described to have a greater effect on sexual quality-of-life than physiological aspects(12). Both physical and psychological effects affect sexual arousal, pleasure and satisfaction. Moreover, sexual quality-of-life after cancer is strongly related to relationship status. Unpartnered AYAs reported less satisfaction with their sexual life than partnered AYAs. They experience distress of sexuality and fear more about their sexual attractiveness(12).

Prevalence of sexual problems is about 50% two years after diagnosis(5, 6). AYAs report several unmet psychosexuality needs, like inadequate support and information regarding sexuality(3, 14, 15). In a survey among AYAs, 82.2% reported the need for information and counselling related to sexuality as being unmet(16). Nonetheless, in a survey assessing oncology providers perceptions on AYAs' unmet needs, only 29.4% of them reported that sexuality and intimacy needs went unmet(17).

Communication about intimacy and sexuality between healthcare professionals (HCPs) and patients is challenging(18). Literature reveals mismatched expectations between HCPs and AYAs. HCPs consider sexuality as non-relevant issue for single AYAs and avoid the topic(19). As a result, single AYAs feel embarrassed to initiate a discussion about sexuality(10, 19). Besides, HCPs are more likely to discuss sexuality with patients with reproductive cancer(19). However, it is known both reproductive and non-reproductive cancers affect sexuality. Equal levels of sexual satisfaction are reported in both groups(12).

Specific knowledge on preferences of AYAs regarding communication about intimacy and sexuality is needed.(20-22). Moreover, to be able to integrate sexual healthcare into practice the view of HCPs is needed. This survey-based study focused on the perspective of AYAs who were diagnosed with cancer between 15-39 years of age and their HCPs. The aim of this study was to determine preferences of AYAs regarding communication about intimacy and sexuality and examine discrepancies between AYA and HCP. We aimed to identify which sexuality-related items are important to discuss, who is held responsible for bringing up sexuality, which barriers AYAs and HCPs face to discuss sexuality and what would help them to enhance communication regarding sexuality. The study outcomes can provide recommendations for HCPs to anticipate AYAs' healthcare-related sexuality and intimacy needs.

Methods

Realisation

In the Netherlands a national AYA-healthcare network was established. This National AYA "Young-and-Cancer" Platform provides an optimal collaborating environment for knowledge translation, scientific research coordination on 'cancer at the AYA-age' and education of state of the art care for AYAs (23). The need to improve care and information related to intimacy and sexuality was emphasized by the network. In association with the department Urology of the Leiden University Medical Center (LUMC), the '*National AYA dreamteam intimacy and sexuality*' was created. This innovative and blended projectgroup, consisting of HCPs, AYAs and researchers was created to investigate shortcomings of provided attention and improve this specific AYA-care. AYA-care in the Netherlands is nurse-led(24). The nurse and oncologist/haematologist are the first contact an AYA has when diagnosed with cancer.

Questionnaire design

The questionnaires were constructed by the dreamteam in collaboration with the authors and based on previous studies of the research group of the LUMC since no validated questionnaire for the aim of our study was available. The department conducted multiple studies using a self-developed questionnaire based on literature and expert review in the past, investigating communication about sexuality in healthcare(25-28). The questionnaire of the current study was adjusted to AYAs based on a search of AYA specific literature and input of the '*National AYA dreamteam intimacy and sexuality*'. A draft version of both questionnaires was sent to a test panel of 6 AYAs and 3 HCPs for evaluation. The HCPs included a urologist-sexologist, sexologist with sexual oncology as field of interest and a psychologist specialized in psychosocial care for AYAs. The pilot panel reviewed the questionnaire with regard to relevance, integrity, structure, lay-out and spelling; some questions were reformulated and open-ended options as well as specific questions about the presence of parents and starting a relationship were added.
The final questionnaires for the AYAs and HCPs contained 39 questions (Appendix 8+9).

Study design

A cross-sectional survey was conducted among AYAs (15-39 years) and HCPs in the Netherlands (29). The distribution of the questionnaire (on paper) for the AYAs happened during the annual Dutch AYA congress in March 2018. This congress is attended by patients, their fellows, HCPs and researchers. During this congress, different important themes regarding AYA-care were discussed and developments were presented.
The questionnaire was also distributed via the online AYA community for private members (AYAs only), facilitated by the National AYA Platform. When members agreed to participation, they were sent a personal link through the online secured system Castor Electronic Data Capture (EDC). After eight weeks a reminder was sent. Exclusion criteria were patients diagnosed under the age of 15 and above the age of 39. There were no restrictions based on cancer type or time from diagnosis(5).

The questionnaire for HCPs was distributed during (1) the congress and (2) a digitalised version of the questionnaire was sent to HCPs who signed up for the congress (n=178). They were sent a personal link through the EDC. The HCPs who already participated during the congress were requested not to contribute again. A reminder to participate was sent after eight weeks. Exclusion criteria were HCPs who did not work with AYAs. Both paper-based and web-based questionnaires were used to optimize response rate(30).

Privacy
Data were anonymously obtained and processed. Only researchers of the projectgroup had access to the questionnaire data.

Statistical analysis
The data were analysed using IBM SPSS Statistics23. Because of relatively low missing data we performed complete case analysis. 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 the list of complaints (table 3) we tested for each complaint separately whether the percentage of AYAs with the complaint was equal to the percentage of HCPs that discussed the complaints. This comparison was done using Pearson's chi-square test; amounts were weighted by number. The same analyses was performed for the list of responsible HCPs (table 4). Each answer option (different HCPs) was tested separately. A two-sided P-value <0.05 was considered statistically significant.

Ethical considerations
Data were collected anonymously and there was no doctor-patient relationship. After consultation with the Medical Ethics Committee of the LUMC, this study appeared not to fall under its jurisdiction and did not require its approval (Number:G19.052).

Results

The survey was administered among 145 AYAs (congress=80, online=65) and 178 HCPs. A total of 61 questionnaires were completed by AYAs (response rate 42.1%) and 54 by HCPs (response rate 30.3%). Five AYA respondents did not meet the inclusion criteria due to a cancer diagnosis before the age of 15; 56 respondents were included for analysis. Two respondents of the HCP-survey were excluded, since they did not meet the criteria of being a HCP to come in contact with AYAs; 52 surveys were included. Demographic and clinical characteristics of the AYAs and HCPs are presented in **Table 1 and Table 2**.

Table 1: Demographic characteristics and clinical variables of the AYAs (n=56)

	n (%)
Age (years)	
Mean 29.4 (SD 5.0, range 20-41)	56 (100.0)
Gender	
Male	12 (21.4)
Female	44 (78.6)
Relationship status	
Single	19 (33.9)
Relationship	31 (55.4)
Married	6 (10.7)
Duration of relationship (years)	
Median 6.5 (range 0.4 – 21)	
Having children	
Yes	10 (17.9)
No	46 (82.1)
Education	
Lower vocational education (VMBO/MAVO/LBO)	1 (1.8)
Intermediate vocational education (MBO)	15 (26.8)
Higher secondary education (HAVO/VWO)	5 (8.9)
Higher education (HBO/WO)	35 (62.5)
Employment	
Yes	28 (50.0)
No, job-seeking	4 (7.1)
No, not able due to disease	15 (26.8)
No, student	9 (16.1)
Cancer type[a]	
Hematological cancer	16 (28.6)
Breast cancer	12 (21.4)
Gynaecological cancer	6 (10.7)
Testicular cancer	5 (8.9)
Brain cancer	4 (7.1)
Sarcoma	4 (7.1)
Thyroid cancer	4 (7.1)
Skin cancer	3 (5.4)
Colorectal cancer	1 (1.8)
Other[b]	2 (3.6)
Type of treatment[c]	
Operation	43 (76.8)
Chemotherapy	43 (76.8)
Radiotherapy	32 (57.1)
Hormonal therapy	8 (14.3)
Immunotherapy	8 (14.3)
Other[d]	8 (14.3)
Age at diagnosis (years)	
Mean 26.0 (SD 5.2, range 15 – 36)	
Time since diagnosis	
3-6 months	4 (7.1)
6 months – 1 year	6 (10.7)
1-2 years	16 (28.6)
2-4 years	17 (30.4)
5-10 years	9 (16.1)
10 years or more	4 (7.1)

a) *One respondent reported two cancer types.*

b) *Anal cancer (n=1), adrenocortical cancer (n=1).*

c) *Most respondents reported multiple types of treatment.*

d) *Stem cell transplantation (n=4), brachytherapy (n=1), radioactive iodine (n=1), missing (n=2)*

Table 2: Demographic characteristics and clinical variables of the health care providers (n=52)

	n (%)
Age (years)	
Mean 41.2 (SD 11.8, range 21-62)	52 (100.0)
Gender	
Male	3 (5.8)
Female	49 (94.2)
Function[a]	
Oncology nurse	25 (48.1)
Nurse practitioner	8 (15.4)
Medical specialist	8 (15.4)
Nurse specialized in AYA care	7 (13.5)
Social worker	3 (5.8)
Other[b]	5 (9.6)
Clinical setting[c]	
University hospital	30 (57.7)
District general teaching hospital	16 (30.8)
District general hospital	2 (3.8)
Independent extramural practice	1 (1.9)
Other[d]	6 (11.5)
Time of practice	
1-2 years	3 (5.8)
3-5 years	13 (25.0)
6-10 years	12 (23.1)
11-15 years	10 (19.2)
>15 years	14 (26.9)
Followed course on sexuality	
Yes, specifically for AYAs	2 (3.8)
Yes, about cancer and sexuality in general	22 (42.3)
No	28 (53.8)

a) Four respondents reported multiple functions.

b) Occupational therapist (n=2), nurse practitioner in training (n=1), coordinator (n=1), missing (n=1)

c) Three respondents reported multiple settings.

d) Rehabilitation center (n=2), hospice (n=1), Care for Cancer Foundation (n=1), home based guidance (n=1)

The influence of disease on sexuality

The majority of the AYAs (75.0%, n=42) indicated that cancer had negative influence on their sexuality. The AYAs were asked in a multiple choice question, containing thirteen possible items, how their sexuality was influenced. The HCPs, who did discuss sexuality with AYAs, were asked which of the same items they discussed with AYAs during a conversation about sexuality. The results are presented in **Table 3**. Both AYA and HCP considered "less sexual desire" (resp. 73.8% and 69.5%), "fatigue" (resp. 64.3% and 65.3%) and "lower lubrication" (in women) (resp. 58.3% and 62%) as most important items. A difference between answers of AYAs and HCPs was found on the item "fear around sex" (resp. 23.8% and 45.3%, p=0.017); HCPs discussed this item more often than AYAs experienced fear around sex.

Table 3

Items[a] that negatively influenced sexuality in AYAs[b] (n=42, women = 36, men = 6)
Items[a] of sexuality that HCPs discussed in female patients (n=50) and male patients (n=45)

	AYA n (%)	HCP n (%)	Significance
Less sexual desire	31 (73.8)	66 (69.5)	NS
Fatigue	27 (64.3)	62 (65.3)	NS
Lower lubrication [c]	21 (58.3)	31 (62)	NS
Self-uncertainty due to changed appearance	24 (57.1)	43 (45.2)	NS
Self-uncertainty due to changed self-image	18 (42.9)	48 (50.5)	NS
Pain during intercourse	18 (42.9)	41 (43.2)	NS
No more pleasure from sex	15 (35.7)	27 (28.4)	NS
Fear around sex	10 (23.8)	43 (45.3)	p = 0.017
Difficulty with orgasm	10 (23.8)	29 (30.5)	NS
Emotional lability	9 (21.4)	33 (34.7)	NS
Erectile dysfunction [d]	1 (16.7)	26 (57.8)	NS

a) Respondents did or did not check the box for each item
b) Most respondents reported multiple items
c) Percentage within women
d) Percentage within men

AYAs' and HCPs' view on sexual healthcare

Nearly all AYAs (91.1%, n=51) and HCPs (98.0%, n=50) considered communication about sexuality as (very) important. Half of the HCPs (47%, n=24) reported to discuss sexuality always or in more than half of the cases. HCPs with training in sexual oncology discussed the topic more often than HCPs without training (63% vs. 45%; p<0.05). Less than half of the AYAs (41.1%, n=23) reported to have received information from a HCP. The majority of 79% (n=44) of the AYAs was not satisfied with the manner the information on intimacy and sexuality was provided. Given reasons for not being satisfied were related to the nature of information as being too general (43.2%, n=19), their expectation that HCPs should have initiated the discussion on the topic (38.6%, n=17) and the opinion that information should have been given earlier (25.0%, n=11).

Answering the question on which HCP would be most suited to discuss intimacy and sexuality according to the AYA, nurse practitioner (61.8%, n=34) and sexologist (49.1%, n=27) were most frequently mentioned. HCPs held the physician (84.3%, n=43) and nurse practitioner (84.3%, n=43) responsible for initiating the topic. Responsibility according to the HCPs and preferences of the AYAs allocated to possible HCP to discuss sexuality with are displayed in **Table 4**. Slightly more than half of the HCPs (56.9%, n=29) mentioned the AYA to be the one to take the initiative to discuss sexuality; no difference was seen between HCPs with training in sexual oncology and HCPs without training (p=0.17). At the same time, HCPs reported that 76.0% of the AYAs never or in less than half of the cases initiate discussion about sexual problems on their own initiative.

Table 4
AYA: options on who would be most suited on discussing sexuality (n=55) [ab]
HCP: options on who should take the initiative on discussing sexuality (n=51) [ab]

	AYA n (%)	HCP n (%)	Significance
Physician	23 (41.8)	43 (84.3)	$p < 0.005$
Nurse practitioner	34 (61.8)	43 (84.3)	$p < 0.005$
The AYA	n/a	29 (56.9)	n/a
Social worker	9 (16.4)	16 (31.4)	NS
Sexologist	27 (49.1)	12 (23.5)	$p = 0.006$
Psychologist	21 (38.2)	10 (19.6)	$p = 0.036$

a) Missing (n=1)
b) Most respondents mentioned multiple options

AYAs' and HCPs' barriers to discuss sexuality

Of all AYAs, 26.8% (n=15) felt like the HCP sufficiently discussed sexuality. Not asking for additional information on their own initiative had mostly to do with feelings of shame (34.2%, n=13) or absence of a romantic relationship (23.7%, n=9). All barriers to discuss sexuality experienced by the AYA are displayed in **Table 5**. Thirty-three percent of the HCPs (n=17) stated to always discuss sexuality with a newly diagnosed AYA. They reported the presence of a third party (52.9%, n=17) and lack of training (42.3%, n=22) as most important barriers for not discussing sexuality with the AYA. HCPs discussed sexuality less often when parents were present (p<0.05). All barriers are displayed in **Table 6**.

Table 5: AYAs' barriers to initiate a conversation about sexuality (n=38)

	n (%)
Feeling of shame	13 (34.2)
I do not have a partner	10 (26.3)
Intimacy and sexuality are not my priority	8 (21.0)
Intimacy and sexuality are private	7 (18.4)
The health care professional does not initiate the conversation	7 (18.4)
Lack of privacy, my parents were present during the conversation	6 (15.8)
I rather discuss it with my partner	5 (13.2)
The health care professional is from the opposite gender	5 (13.2)
I am too sick to discuss intimacy and sexuality	4 (10.5)
The health care professional is too busy	3 (7.9)
Nothing can be done about it	2 (5.3)
The health care professional does not seem open to this	2 (5.3)
The age of the health care professional	2 (5.3)
Lack of privacy, my partner was present during the conversation	2 (5.3)
I don't want to talk about it	1 (2.6)
This is no task for the health care professional	0
Lack of privacy, other health care professionals were present during the conversation	0

Table 6: Reasons for the healthcare professional not to discuss sexuality with an AYA. (n=52)[a]

	Agree/strongly agree *n (%)*	Partly disagree/ agree *n (%)*	Strongly disagree/disagree *n (%)*
Presence of a third party	27 (52.9)	18 (35.3)	6 (11.8)
Lack of training	22 (42.3)	14 (26.9)	16 (30.8)
AYA's parents were present	18 (36.7)	22 (44.9)	9 (18.4)
Lack of knowledge	17 (32.7)	13 (25.0)	22 (42.3)
Reasons related to language/ethnicity	16 (31.4)	18 (35.3)	17 (33.3)
Reasons related to culture/religion	14 (27.5)	18 (35.3)	19 (37.3)
Lack of time	10 (19.6)	19 (37.3)	22 (43.1)
No angle or reason for asking	10 (19.6)	13 (25.5)	28 (54.9)
My workspace is not quiet	8 (15.7)	6 (11.8)	37 (72.5)
AYA is too ill	6 (11.8)	15 (29.4)	30 (58.8)
I feel uncomfortable	5 (9.6)	16 (30.8)	31 (59.6)
AYA is not ready	3 (6.0)	16 (32.0)	31 (62.0)
Sexuality is a private matter	3 (5.9)	14 (26.9)	34 (66.7)
Not feeling a connection with the AYA	2 (3.9)	11 (21.6)	38 (74.5)
AYA has no sexual problems	2 (4.0)	9 (18.0)	39 (78.0)
Age difference between you and AYA	2 (3.9)	5 (9.8)	44 (86.3)
Afraid to offend the AYA	2 (3.8)	4 (7.7)	46 (88.5)
AYA doesn't have a partner	1 (2.0)	7 (13.7)	43 (84.3)
It's someone else's task	1 (2.0)	4 (7.8)	46 (90.2)
AYA is the opposite gender	-	9 (18.0)	41 (82.0)
No resources to refer the AYA	-	2 (3.9)	49 (96.1)

a) Not all percentages are equal due to missing data

What do they need to discuss sexuality?

According to AYAs, the best way for providing information is through a website (66.1%, n=37) or via a conversation with a HCP (64.3%, n=36). Their preferences according to different ways for information supply are displayed in **Figure 1**. As to the AYAs preferred moment of getting information, they mentioned the following options: before treatment (64.3%, n=36), followed by during treatment (51.8%, n=29) and after treatment (50.0%, n=28).

Frequently mentioned ways by HCPs that may help them discuss sexuality with AYAs were leaflets about sexuality to give to the AYA (75%, n=39) and training to improve skills on discussing the matter (71.2%, n=37), easy ways to refer the AYA to the department of sexology (32.7%, n=17) and more time with the patient (32.7%, n=17). HCPs without training in sexual oncology were more interested in the leaflets about sexuality than the HCPs with training (p<0.05).

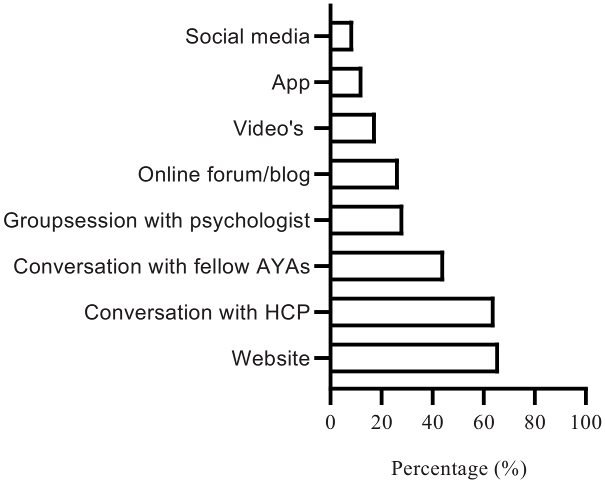


Figure 1: The best way for providing information about intimacy and sexuality according to the AYAs. (AYAs: adolescents and young adults; HCPs: health care professionals)

Discussion

The purpose of this study was to determine preferences of AYAs regarding communication about intimacy and sexuality and examine discrepancies between AYA and HCP. AYAs and HCPs almost unanimously agreed that communication about sexuality is important. However, approximately half of the AYAs and HCPs reported not to discuss sexuality in the consultation room. When sexuality is discussed, HCPs seem to discuss the relevant items according to the AYA. AYAs preferred to discuss sexuality with a nurse practitioner or sexologist. However, HCPs held physicians and nurse practitioners responsible. To enhance communication about sexuality, HCPs would like to have leaflets about sexuality to give to the AYA and additional training. AYAs would prefer to get information before start of treatment via a website and HCP.

According to our study, detailed provision of information before treatment is necessary. Early information provision may contribute to realistic expectations of the impact of cancer treatment on sexuality and may reduce possible distress due to sexual problems(20). Besides, further evaluation of sexuality related needs should come to pass during follow-up since problems with sexuality can arise after treatment(31). Dobinson et al. showed similar results, proposing that intimacy and sexuality should be discussed on several occasions throughout the treatment trajectory and sexual healthcare should be incorporated in survivorship care plans (3).

As our findings, previous research emphasized AYAs' need for support from HCPs regarding sexual concerns(3, 18). HCPs reported barriers to discuss sexuality in the current study are similar to barriers reported by adult oncology HCPs, namely lack of training and feeling of embarrassment(6, 32-34). In concordance with existing literature, presence of a third party was mentioned as specific barrier for HCPs in AYA-care(35). It is known that most patients will not initiate a discussion about sexuality by themselves(15). For the responding AYAs this had mostly to do with feelings of shame or the present of the parents(18). Moreover, AYAs might not be aware that their issues with sexuality are related to cancer treatment due to limited sexual self-knowledge or sexual immaturity(15). Cancer threats normal sexual development. Limited sexual-health knowledge can be caused by developmental age, reduced contact with pears and reduced contact at school due to the cancer(3, 36). Therefore it is important that HCPs address the issue and not rely on the initiative of AYAs. Taking in mind AYAs' and HCPs' barriers, it would be helpful if HCPs routinely offer AYAs some time alone with them(18). In addition, training for HCPs on effective communication strategies to initiate and facilitate a discussion about sexuality may lead to better comfort by both AYA and HCP(35). Moreover, according to our survey HCPs would be helped with the availability of written material to give to the AYA.

In our survey a discrepancy was seen in which HCP AYAs considered as most suitable for discussing sexuality with and to whom HCPs allocate the responsibility within their oncology team to discuss sexuality. AYAs preferred to discuss sexuality with a sexologist. A conversation with a sexologist is not part of standard care in the Netherlands. To deliver optimal sexual healthcare, clear defined roles within the oncological team are required(37). For example, physicians could name sexual side effect and check for these side effects during treatment and follow-up. The nurse practitioner, or if needed a sexologist, could support patients with sexual changes due to cancer (37). These findings indicate a role for practical training for HCPs to create awareness for sexual problems, be able to provide information or else know about referral options(14).

This study was the first Dutch nation-wide survey on sexuality related care for AYAs. The design made it possible to conduct the study from the perspective of AYAs and HCPs. The study confirms some results of existing literature on discussion about sexuality, but distinguished itself by involving both AYAs and HCPs and examine discrepancies between them. Some limitations should be taken into account when interpreting the results. In spite of the considerable response rate to a patient survey with a sensitive topic (42.1%), the study population consisted of 56 AYAs. This is comparable with other surveys among patient about communication in sexuality(26, 38). This response rate is slightly higher in comparison with surveys with other topics among AYAs in the Netherlands (29%) (39, 40). The response ratio of the HCPs was low, yet comparable to the response rate of other questionnaires among HCPs(25, 34, 41). Selection bias could have been present. People attending a cancer symposium or actively respond to an online questionnaire request are not necessarily a representative sample of the AYA population or HCPs who work with AYAs. Previous research examined AYAs' sexual satisfaction and reported women to having sex less often post-cancer and lower levels of satisfaction with their sexual lives than men(6, 42). This might be an explanation for the male/female ratio of 20/80 in our survey whereas the male/female ratio among AYAs in the Netherlands is about 40/60 (29). Moreover, the unequal distribution can be explained by recruitment via an online forum. 71% of the members of the forum are women(43). It could be that women are more likely to seek online support(44). They may therefore be more prepared to fill out the questionnaire, but also more likely to be user of information about sexuality(43, 45). There could also be question of recall bias. This survey-based study relied on the memory of participants. The majority of AYAs was diagnosed over one year ago. However, sexual problems are likely to continue on the long-term and many cancer survivors do not feel prepared for sexual issues(10). Therefore experiences of respondents diagnosed some time ago are of importance. Furthermore, we used a non-validated questionnaire since there were no validated questionnaires available for the aim. Questionnaires were designed in co-creation with AYAs and HCPs to highlight relevant issues. Further research could focus on improving existing information and educate HCPs. Our results could give guidance on the areas that need enhancement and serve as pilot for further research.

Conclusion

According to the AYAs, sexuality and intimacy is not being discussed enough by HCPs and existing information is not sufficient. It is recommended to address the topic by trained HCPs on multiple occasions throughout the cancer trajectory and information on websites needs to be more focussed on AYAs. The discrepancy between AYAs and HCPs illustrates the importance of patient participation to prioritize their own care according to their needs on intimacy and sexuality.

REFERENCES

1. Maslow AH. A Theory of Human Motivation. Psychological Review. 1943;50(4):370-96.
2. Zebrack BJ. Psychological, social, and behavioral issues for young adults with cancer. Cancer. 2011;117(10 Suppl):2289-94. Epub 2011/05/20. doi: 10.1002/cncr.26056. PubMed PMID: 21523748.
3. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(2):135-45. Epub 2016/01/27. doi: 10.1089/jayao.2015.0022. PubMed PMID: 26812456.
4. Olsson M, Steineck G, Enskar K, Wilderang U, Jarfelt M. Sexual function in adolescent and young adult cancer survivors-a population-based study. J Cancer Surviv. 2018;12(4):450-9. Epub 2018/03/07. doi: 10.1007/s11764-018-0684-x. PubMed PMID: 29508213.
5. Wettergren L, Kent EE, Mitchell SA, Zebrack B, Lynch CF, Rubenstein MB, et al. Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study. Psychooncology. 2017;26(10):1632-9. Epub 2016/05/31. doi: 10.1002/pon.4181. PubMed PMID: 27240019.
6. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405. Epub 2017/11/18. doi: 10.1002/cncr.31030. PubMed PMID: 29149503.
7. Szalda D, Schapira MM, Jacobs LA, Palmer SC, Vachani C, Metz J, et al. Survivorship Care Planning for Young Adults After Cancer Treatment: Understanding Care Patterns and Patient-Reported Outcomes. Journal of adolescent and young adult oncology. 2018;7(4):430-7. Epub 2018/03/24. doi: 10.1089/jayao.2017.0112. PubMed PMID: 29570983.
8. Potosky AL, Davis WW, Hoffman RM, Stanford JL, Stephenson RA, Penson DF, et al. Five-year outcomes after prostatectomy or radiotherapy for prostate cancer: the prostate cancer outcomes study. J Natl Cancer Inst. 2004;96(18):1358-67. Epub 2004/09/16. doi: 10.1093/jnci/djh259. PubMed PMID: 15367568.
9. Adams E, Boulton MG, Horne A, Rose PW, Durrant L, Collingwood M, et al. The effects of pelvic radiotherapy on cancer survivors: symptom profile, psychological morbidity and quality of life. Clin Oncol (R Coll Radiol). 2014;26(1):10-7. Epub 2013/09/03. doi: 10.1016/j.clon.2013.08.003. PubMed PMID: 23992740.
10. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9. Epub 2012/09/26. doi: 10.1200/jco.2012.41.7915. PubMed PMID: 23008322.
11. Zhou ES, Falk SJ, Bober SL. Managing premature menopause and sexual dysfunction. Curr Opin Support Palliat Care. 2015;9(3):294-300. Epub 2015/07/15. doi: 10.1097/SPC.0000000000000156. PubMed PMID: 26155020.
12. Mutsch J, Friedrich M, Leuteritz K, Sender A, Geue K, Hilbert A, et al. Sexuality and cancer in adolescents and young adults - a comparison between reproductive cancer patients and patients with non-reproductive cancer. BMC cancer. 2019;19(1):828. Epub 2019/08/24. doi: 10.1186/s12885-019-6009-2. PubMed PMID: 31438895; PubMed Central PMCID: PMCPMC6704507.
13. Flynn KE, Jeffery DD, Keefe FJ, Porter LS, Shelby RA, Fawzy MR, et al. Sexual functioning along the cancer continuum: focus group results from the Patient-Reported Outcomes Measurement Information System (PROMIS(R)). Psycho-oncology. 2011;20(4):378-86. Epub 2010/09/30. doi: 10.1002/pon.1738. PubMed PMID: 20878833; PubMed Central PMCID: PMCPMC3013236.
14. Mitchell L, Lewin J, Dirks J, Wang K, Tam S, Katz A, et al. Sexual Health Issues for the Young Adult with Cancer: An International Symposium Held During the First Global Adolescents and Young Adults Cancer Congress (Edinburgh, United Kingdom). Journal of adolescent and young

adult oncology. 2018;7(2):153-63. Epub 2018/01/11. doi: 10.1089/jayao.2017.0067. PubMed PMID: 29319398.

15. Bolte S, Zebrack B. Sexual issues in special populations: adolescents and young adults. Seminars in oncology nursing. 2008;24(2):115-9. Epub 2008/04/30. doi: 10.1016/j.soncn.2008.02.004. PubMed PMID: 18442674.

16. Zebrack B. Information and service needs for young adult cancer patients. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2008;16(12):1353-60. Epub 2008/04/04. doi: 10.1007/s00520-008-0435-z. PubMed PMID: 18386075.

17. Kirchhoff AC, Fowler B, Warner EL, Pannier ST, Fair D, Spraker-Perlman H, et al. Supporting Adolescents and Young Adults with Cancer: Oncology Provider Perceptions of Adolescent and Young Adult Unmet Needs. Journal of adolescent and young adult oncology. 2017;6(4):519-23. Epub 2017/06/13. doi: 10.1089/jayao.2017.0011. PubMed PMID: 28605222.

18. Frederick NN, Revette A, Michaud A, Bober SL. A qualitative study of sexual and reproductive health communication with adolescent and young adult oncology patients. Pediatric blood & cancer. 2019;66(6):e27673. Epub 2019/02/16. doi: 10.1002/pbc.27673. PubMed PMID: 30767372.

19. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94. Epub 2016/10/25. doi: 10.1016/j.jsxm.2016.09.005. PubMed PMID: 27686697.

20. Robertson EG, Sansom-Daly UM, Wakefield CE, Ellis SJ, McGill BC, Doolan EL, et al. Sexual and Romantic Relationships: Experiences of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(3):286-91. Epub 2016/02/18. doi: 10.1089/jayao.2015.0061. PubMed PMID: 26885746.

21. Martins A, Taylor RM, Lobel B, McCann B, Soanes L, Whelan JS, et al. Sex, Body Image, and Relationships: A BRIGHTLIGHT Workshop on Information and Support Needs of Adolescents and Young Adults. Journal of adolescent and young adult oncology. 2018;7(5):572-8. Epub 2018/05/10. doi: 10.1089/jayao.2018.0025. PubMed PMID: 29742008.

22. Stinson JN, Jibb LA, Greenberg M, Barrera M, Luca S, White ME, et al. A Qualitative Study of the Impact of Cancer on Romantic Relationships, Sexual Relationships, and Fertility: Perspectives of Canadian Adolescents and Parents During and After Treatment. Journal of adolescent and young adult oncology. 2015;4(2):84-90. Epub 2016/01/27. doi: 10.1089/jayao.2014.0036. PubMed PMID: 26812556.

23. Nationaal AYA ‘Jong & Kanker’ Platform [4 September 2018]. Available from: https://aya4net.nl/.

24. Olsen PR SS. Nursing Adolescents and Young Adults with Cancer. Developing Knowledge, Competence and Best Practice: Springer; 2018.

25. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15. Epub 2015/06/09. doi: 10.1016/j.ejon.2015.05.005. PubMed PMID: 26051072.

26. Grondhuis Palacios LA, Krouwel EM, den Oudsten BL, den Ouden MEM, Kloens GJ, van Duijn G, et al. Suitable sexual health care according to men with prostate cancer and their partners. Support Care Cancer. 2018. Epub 2018/06/08. doi: 10.1007/s00520-018-4290-2. PubMed PMID: 29876833; PubMed Central PMCID: PMCPMC6209012.

27. Nicolai MP, van Bavel J, Somsen GA, de Grooth GJ, Tulevski, II, Lorsheyd A, et al. Erectile dysfunction in the cardiology practice-a patients' perspective. American heart journal. 2014;167(2):178-85. Epub 2014/01/21. doi: 10.1016/j.ahj.2013.10.021. PubMed PMID: 24439978.

28. Dikmans RE, Krouwel EM, Ghasemi M, van de Grift TC, Bouman MB, Ritt M, et al. Discussing sexuality in the field of plastic and reconstructive surgery: a national survey of current practice in the Netherlands. European journal of plastic surgery. 2018;41(6):707-14. Epub

2018/12/14. doi: 10.1007/s00238-018-1452-x. PubMed PMID: 30524177; PubMed Central PMCID: PMCPMC6244988.

29. What Should the Age Range Be for AYA Oncology? Journal of adolescent and young adult oncology. 2011;1(1):3-10. Epub 2011/03/01. doi: 10.1089/jayao.2011.1505. PubMed PMID: 26812562.

30. Zuidgeest M, Hendriks M, Koopman L, Spreeuwenberg P, Rademakers J. A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care. Journal of medical Internet research. 2011;13(3):e68. Epub 2011/09/29. doi: 10.2196/jmir.1241. PubMed PMID: 21946048; PubMed Central PMCID: PMCPMC3222165.

31. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]. 2014;12(1):41-53. Epub 2015/07/29. doi: 10.1016/j.ejcsup.2014.03.004. PubMed PMID: 26217165; PubMed Central PMCID: PMCPmc4250536.

32. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601. Epub 2011/03/12. doi: 10.1002/pon.1947. PubMed PMID: 21394821; PubMed Central PMCID: PMCPmc3149787.

33. Zebrack BJ, Block R, Hayes-Lattin B, Embry L, Aguilar C, Meeske KA, et al. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. Cancer. 2013;119(1):201-14. Epub 2012/06/30. doi: 10.1002/cncr.27713. PubMed PMID: 22744865.

34. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87. Epub 2015/07/18. doi: 10.1016/j.ejso.2015.06.009. PubMed PMID: 26184851.

35. Frederick NN, Campbell K, Kenney LB, Moss K, Speckhart A, Bober SL. Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians and adolescent and young adult patients: The clinician perspective. Pediatric blood & cancer. 2018;65(8):e27087. Epub 2018/04/27. doi: 10.1002/pbc.27087. PubMed PMID: 29697189.

36. Evan EE, Kaufman M, Cook AB, Zeltzer LK. Sexual health and self-esteem in adolescents and young adults with cancer. Cancer. 2006;107(7 Suppl):1672-9. Epub 2006/08/15. doi: 10.1002/cncr.22101. PubMed PMID: 16906508.

37. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9. Epub 2011/01/01. doi: 10.4066/amj.20111047. PubMed PMID: 23386876; PubMed Central PMCID: PMCPMC3562918.

38. Den Ouden MEM, Pelgrum-Keurhorst MN, Uitdehaag MJ, De Vocht HM. Intimacy and sexuality in women with breast cancer: professional guidance needed. Breast cancer (Tokyo, Japan). 2019;26(3):326-32. Epub 2018/10/27. doi: 10.1007/s12282-018-0927-8. PubMed PMID: 30361832.

39. Thewes B, Kaal SEJ, Custers JAE, Manten-Horst E, Jansen R, Servaes P, et al. Prevalence and correlates of high fear of cancer recurrence in late adolescents and young adults consulting a specialist adolescent and young adult (AYA) cancer service. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018;26(5):1479-87. Epub 2017/11/24. doi: 10.1007/s00520-017-3975-2. PubMed PMID: 29168035; PubMed Central PMCID: PMCPMC5876258.

40. Kaal SEJ, Husson O, van Duivenboden S, Jansen R, Manten-Horst E, Servaes P, et al. Empowerment in adolescents and young adults with cancer: Relationship with health-related quality of life. Cancer. 2017;123(20):4039-47. Epub 2017/07/12. doi: 10.1002/cncr.30827. PubMed PMID: 28696580; PubMed Central PMCID: PMCPMC5655905.

41. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal

of sexual medicine. 2015;12(9):1927-39. Epub 2015/09/19. doi: 10.1111/jsm.12969. PubMed PMID: 26381533.

42. Geue K, Schmidt R, Sender A, Sauter S, Friedrich M. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. Psychooncology. 2015;24(11):1368-76. Epub 2015/04/01. doi: 10.1002/pon.3805. PubMed PMID: 25826748.

43. Kaal SE, Husson O, van Dartel F, Hermans K, Jansen R, Manten-Horst E, et al. Online support community for adolescents and young adults (AYAs) with cancer: user statistics, evaluation, and content analysis. Patient preference and adherence. 2018;12:2615-22. Epub 2018/12/26. doi: 10.2147/ppa.S171892. PubMed PMID: 30584285; PubMed Central PMCID: PMCPMC6287522.

44. Fasciano KM, Souza PM, Braun I, Trevino K. An Innovative Website in the United States for Meeting the Emotional and Supportive Care Needs of Young Adults with Cancer. Journal of adolescent and young adult oncology. 2015;4(1):44-9. Epub 2016/01/27. doi: 10.1089/jayao.2014.0035. PubMed PMID: 26812430.

45. Sawyer SM, McNeil R, McCarthy M, Orme L, Thompson K, Drew S, et al. Unmet need for healthcare services in adolescents and young adults with cancer and their parent carers. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2017;25(7):2229-39. Epub 2017/03/07. doi: 10.1007/s00520-017-3630-y. PubMed PMID: 28261754.

Chapter 8: Discussing sexual health with adolescents and young adults with cancer: a qualitative study among healthcare providers

Albers LF, Bergsma FB, Mekelenkamp H, Pelger RCM,
Manten-Horst E, Elzevier HW

Journal of Cancer Education. 2020 Jun 17.

Introduction

Sexual health is a multidimensional concept, the definition of which lacks consensus in the literature. For the purpose of this study, sexual health is compromises of sexual self-awareness, sexual function, sexual relationships and intimacy(1-3). These issues usually arise during adolescence or young adulthood(4, 5). Cancer during this period may hinder normal sexual development as cancer and its treatment are associated with sexual problems(6-8). Hence, there is a risk of a delay in sexual development in adolescent and young adults with cancer (AYAs; 15-39 years old)(9, 10). As a result, AYAs are more likely to have impaired sexual function, decreased libido and lower self-esteem(6). Changes in body and body image are a major concern(11). Issues with sexual health can have a negative impact on the development of intimate relationships which are of importance in coping with disease, and so it is necessary to pay attention to them in order to aid to psychological acceptance and recovery(9, 12, 13).

As well as desire for knowledge, AYAs have a need for support with the effect of cancer and its treatment on their sexual health. In a survey among 217 AYAs, 82% reported an unmet need regarding information and counselling on sexual health (14). In addition, AYAs experience a lack of communication with healthcare providers (15). In a retrospective study among 427 AYAs, only 12% had had a discussion about sexual health within 6 months of the initial consultation (16). AYAs' discomfort and the presence of parents and family make it difficult for them to initiate a conversation themselves (15). AYAs do, however, think that communication about sexual health with healthcare providers is important, as well as support in dealing with sexual problems, such as coping with physical side effects, issues around self-image and learn to discuss their sexual concerns (11, 12, 17). AYAs reported preferring to receive support in-person from their healthcare providers (15, 17).

At the same time, sexual health is a challenging topic for healthcare providers to discuss with AYAs. There are numerous barriers that healthcare providers face, including lack of knowledge, lack of resources, low priority, presence of parents or family, their own discomfort, lack of time and the lack of a longitudinal relationship with the patient(18-22). Furthermore, there is a mismatch in expectations between AYAs and healthcare providers(20). Although the majority of AYAs report an unmet need, in a survey accessing this aspect, only 28% of the oncology healthcare providers reported that AYAs' need for sexual health went unmet(14).

Existing studies mainly focus on discussing fertility rather than sexual health, a topic which clinical teams need to address(11, 23-26) . As AYAs prefer a conversation in person about sexual health, it is important to know the practice and ideas of the healthcare providers in order to arrange realistic and feasible tools for them to enhance communication about sexual health. Therefore, with a view to improving sexual health care for AYAs, this study aims to gain insight into the views of healthcare providers on best practices.

Methods

Study design
This is a qualitative investigation using semi-structured interviews with internist-oncologists, internist-hematologists, nurse specialists and nurses specialized in AYA care regarding discussing sexual health(27). This study was performed in collaboration with the Dutch "National AYA 'Young and Cancer' Network" (https://aya4net.nl/).

Participants and recruitment
There are eight academic hospitals with a specialization in AYA care in the Netherlands. Each of these hospitals has an AYA-team consisting of an internist as team leader, specialized nurses and allied healthcare providers. AYA-care in the Netherlands is patient-centered and nurse-led(28). The nurse and internist-oncologists or internist-hematologists are the first contact an AYA has when diagnosed with cancer. Therefore, this study included nurses and internist-oncologists or internist-hematologists, but no allied healthcare providers. In this paper, we describe them as 'doctors' and 'nurses', lumped together as healthcare providers. The doctors and nurses of each of the eight AYA-teams were invited to participate by e-mail. Healthcare providers with at least 1 year's work experience with AYAs were eligible for this study. Fourteen healthcare providers agreed to participate in the study. Reasons for invited healthcare providers to decline the invitation were participation in other studies and lack of time. The participants who agreed to participate were contacted by phone to make an appointment for the interview.

Data collection
All interviews were performed by one of the authors (FB). As a medical student, she had followed trainings in interview techniques. Two test interviews were performed and evaluated to optimize technique applied. She had no connection with the participants prior to the interviews. In total, 13 interviews were conducted. Twelve of the participants were interviewed individually; one duo interview was performed as requested by two nurses. All interviews were conducted in person at the workplace of the interviewee, chosen by the interviewee. The duration of the interviews was approximately one hour. After every two (new) interviews, the interviews were read and coded by two authors (FB and LA) and evaluated with regard to technique and quality. The set of questions set did not change. However, the interviewer focused more on facilitators for discussing sexual health than the exact current practice of the participants.

Supplementary Table S1 (appendix 10) presents the semi-structured interview question set. The set is based on expert knowledge and literature investigating communication about sexual health in healthcare. Prior to the start of each interview, demographic information was checked by e-mail, including job, gender, age, number of years of experience in practice with AYAs, number of AYA patients seen per year, both in - and outpatient care, training in sexual health and use of guidelines. Interviews were audio-recorded and transcribed verbatim. After each interview, the interviewer wrote a memo about the ambiance of the interviews and the themes discussed.

Data analysis
A thematic analysis was used to analyze the data(29). First, transcripts were read thoroughly so that the two study authors (LA and FB) became familiar with the data; they

were then coded independently. Discrepancies in coding were discussed with a third author (HE) until consensus was reached. Coding was supported by software program Atlas.ti.; 129 codes were defined. The codes were categorized into groups and later different themes were defined. Thematic saturation was reached, i.e. no new themes were mentioned by the interviewees, after the 10th interview. This indicated that this sample of 14 healthcare providers was adequate for capturing a range of responses. To be sure that no new topics were mentioned, three interviews continued after the 10th interview.

Ethical considerations

This study, the aim of which was to optimize the care process, was conducted among healthcare providers who participated voluntarily. After consultation with the Medical Ethics Committee of the LUMC, this study was considered as exempt from requiring ethical approval.

Results

Participants characteristics

The sample included six doctors and eight nurses **(Table 1)**. Seventy-nine percent (n=11) were female. Mean age of the participants was 48 years. Participants came from seven (out of eight) different hospitals in the Netherlands. Two nurses and one doctor had followed a training on sexology. Two of the participants used guidelines to inform patients about sexual side effects of treatment.

Table 1: Demographics of participants (n=14)

Characteristics	
Function	
Internist: oncologist / hematologist	5 / 1
Nurse: specialists	8
Identified gender	
Female	11
Male	3
Age of participant in years	
30-40	3
41-50	5
51-60	5
61-70	1
Years of experience in practice with AYAs	
1-5	2
6-10	3
11-15	2
16-20	0
>20	7
No. of contacts with AYA patients per year	
10-100	5
101-200	1
201-300	3
301-400	0
>400	5

Themes

'Being responsible for facilitating patients' needs regarding sexual health' was defined as the overall theme of our study. The following five major themes were identified: (1) being responsible for bringing up the topic of sexual health, (2) finding optimal timing to discuss sexual health, (3) acquiring optimal knowledge to enable discussion of sexual health, (4) facilitating communication about sexual health, (5) providing informative material for AYAs.

Theme 1: Being responsible for bringing up the topic of sexual health

All participants emphasized the importance of discussing sexual health with AYAs. Some doctors described discussing sexual health as a role for nurses. They assumed that nurses have more time to discuss the topic and patients might experience a lower barrier talking to nurses. Some doctors noted discussing sexual health as being a role for the themselves as well. They assumed they had a better doctor-patient relationship due to the frequent number of contacts they have with the AYAs. Some nurses stated that it was their responsibility because they see the patients more often, they assumed that patients experience a lower barrier to talking about sexual health and reported having time to discuss the topic. Others felt discussing sexual health was a shared responsibility and some stated that it does not matter who talked about it as long as the topic was discussed. A doctor highlighted the importance of clearly defined roles within the medical team regarding discussing this theme. He explained: *"It should be clear who is responsible for discussing sexual health, otherwise it will not happen" (respondent 008).*

Theme 2: Finding optimal timing to discuss sexual health

Participants denoted different ideal moments for discussing sexual health during the treatment process. All participants stated that there is not one ideal moment to discuss sexual health. Some participants preferred at least to address the topic when the initial treatment plan is discussed. They consider it important to create awareness about this topic before starting treatment, by addressing possible sexual side-effects. Some doctors argued to avoid this at the first appointment. They believe that the time available for giving a comprehensive explanation about the treatment itself is already limited. Sexual health does not form a priority at that moment. One stated: *"Patients remember approximately 20% of a conversation; the more you discuss, the less they remember. I discuss more urgent side-effects first, like fever after chemotherapy" (respondent 003).* Some healthcare providers preferred discussing sexual health during or at the end of treatment, in order to address possible sexual concerns directly, or opted for making a new appointment. *"During the treatment process, it might be useful to make an extra appointment to discuss unsolved subjects, like sexual health"(respondent 003).* Some healthcare providers described discussing sexual health only when there was a high chance of sexual problems, for instance after pelvic surgery. Eight healthcare providers mentioned the power of repetition; they consider it insufficient to discuss it only once.

Theme 3: Acquiring knowledge to enable discussion of sexual health

Participants identified two major facilitators for achieving sufficient knowledge to discuss sexual health with the AYA: 1) education of the healthcare provider and 2) multidisciplinary approach.

Most healthcare providers did not receive education or training in sexology; according to them, this could be a facilitator for discussing the topic. They suggested that education during medical and nursing school would be ideal. *"If the threshold for talking about sexual health is already lowered by education, it will be easier to talk about this subject later in your career" (respondent 004).* Additionally, training could be provided for oncologists and oncology nurses. Other healthcare providers mentioned that an elective way of education would be ideal; for example, oncosexology training as part of an oncology course or a congress. The training should contain at least basic knowledge on cancer and sexual health and practical information on how to start a conversation about sexual health.

Healthcare providers described a need for a multidisciplinary approach to sexual health related problems since they experience lack of knowledge and lack of expertise. Initiating a conversation about sexual health would feel more comfortable if there is an opportunity to discuss patients' problem in a multidisciplinary team meeting. Additionally, they consider it important to have the option to refer AYAs to a sexologist within their hospital. One explained: *"When I notice a problem with sexual health or the AYA has a question about sexual health, I discuss this in a multidisciplinary meeting in order to give good advice to the AYA" (respondent 004).*

Theme 4: Facilitating communication about sexual health

Two subthemes were defined: (1) tools for facilitating communication and (2) communication strategies to facilitate discussing sexual health with AYAs during a consultation.

Subtheme 1: tools for facilitating communication

Various useful tools were mentioned as being helpful for improving communication about sexual health: (1.1) the use of a self-report questionnaire to complement the consultation, (1.2) informative material to hand out and (1.3) a checklist for healthcare providers in the electronic patient dossier.

Most healthcare providers suggested the use of a self-report questionnaire which could be filled out by the AYA before the consultation with a doctor or nurse. (Both doctors and nurses conduct consultations.) It could include questions about sexual health in order to explore specific problems. One explained: *"The AYA will be triggered to think about the subject and the healthcare provider will be more alert to discussing the topic" (respondent 003).* Using the self-report questionnaire, the healthcare provider can prepare specific topics and it may lower the threshold for initiating a discussion about sexual health.

All healthcare providers also identified the availability of information material about sexual health as a facilitating tool. They consider it as helpful to be able to give some form of written information to the AYA. Furthermore, a checklist in the electronic patient dossier about whether sexual health is discussed, was highlighted by several healthcare providers as a useful tool. They stated it would be helpful to become more aware of the topic. *"AYAs meet multiple doctors and nurses. A checklist would be helpful to record if and when sexual health is discussed" (respondent 009).*

Subtheme 2: Communication strategies to facilitate discussing sexual health with AYAs during a consultation

Healthcare providers described different communication strategies to facilitate discussing sexual health with AYAs in the consulting room. Six different strategies were identified: (2.1) actively initiating a discussion, (2.2) finding the right moment, (2.3) normalization of the subject, (2.4) actively returning to the subject, (2.5) use of humor, (2.6) ensuring privacy.

2.1 Actively initiating a discussion

One of the strategies which was frequently mentioned was to actively initiate a discussing of sexual health, instead of waiting for the AYA to bring up the topic. When the healthcare provider initiate the topic, it might be easier for AYAs to share their concerns. *"Sometimes, AYAs dare not ask these questions" (respondent 001).* Initiating the topic in response to another related topic, like fertility, was also recommended. *"You actually need some triggers to start a discussion about sexual health. For example, hormone levels is a good topic for making it (sexual health) discussable" (respondent 008)* or *"Fertility is linked to sexual health. It is easier to start about sexual health when discussing fertility" (respondent 011).*

2.2 Finding the right moment

Some participants stated they preferred addressing sexual health in reaction to a question from the AYA. *"I don't want to meddle, I react to patients' questions" (respondent 004).*

A question from the AYA can be used as an opening to explain more about sexual health and to go into more detail. *“Sometimes patients themselves come along with a specific questions (about sexual health). That gives me the opportunity to discuss the broader topic” (respondent 002).*

2.3 Normalization of the subject

Participants considered it important to normalize the subject. They explained: *"It would be helpful if we normalize sexual health and ask about it just like asking about diet or weight” (respondent 002).* Another way of normalizing the topic could be to emphasize that sexual health concerns are common. *“You can tell the AYA that it is quite common to have issues with sexual health and that they are not an exception” (respondent 003).*

2.4 Actively returning to the subject

Some participants described actively returning to the topic of sexual health after the subject has been discussed in order to evaluate concerns. *“When I advise the AYA about sexual health concerns, I always come back to the topic the next time. I check whether the advice worked well" (respondent 004).*

2.5 Use of humor

Some of the healthcare providers suggested the use of humor as a strategy to bring up the topic of sexual health. *"A bit of humor helps to bring a delicate subject like sexual problems out into the open” (respondent 012)*. Another explained: *“Humor and sexuality are a good combination. It is a way of making the topic less loaded” (respondent 004).*

2.6 Ensuring privacy

For an open discussion about sexual health, participants recommended ensuring having time alone with the AYA, without parents being present. *“There is a world of difference between what AYAs tell if the parents are absent. The AYAs tend to ask more question regarding sexual health when they are alone” (respondent 005).*

Theme 5: Providing informative material for AYAs

Participants were asked which elements should definitely be included in content of ideal information about sexual health for AYAs based on questions they receive from AYAs and items they consider to be important. Most healthcare providers stated that possible consequences and side effects of the cancer and its treatment should be included. Specific complaints per cancer type and treatment should be incorporated. One explained: *“If the information is too general, they may again have doubts: does this also apply to me?" (respondent 001).* Healthcare providers considered it important to include physiology of the healthy body, regarding sexual health, into the informative material. In this way it is assumed that the effect of cancer on sexual health is easier to understand. Also the possible consequences for the partner, the influence on the relationship and the influence on dating were mentioned here.

Some healthcare providers mentioned including the dos and don’ts regarding sexual health for AYAs. They notice AYAs being confused about whether or not it is allowed to kiss or have sex during chemotherapy or when to use a condom. It was also considered important to explain the rationale behind these statements in order to prevent possible ‘fables’. One healthcare provider explained: *"There are a lot of fables about what is and isn't allowed. I think healthcare providers caused this, because we give instructions without explaining the reason why" (respondent 003).*

Moreover, practical tips in managing the side effects of the cancer and treatment were highlighted by several healthcare providers. As well as tips for physical and physiological management, tips for dating and to initiate a discussion on sexual health with their partner or healthcare provider were considered important.

Most participants agreed that information in the form of educational material about sexual health should be offered to the AYA. It is considered important that the material is accessible to every patient and healthcare provider and that the information about sexual health has a place amongst other subjects. Digital information via a website was considered by the majority of the healthcare providers to be the ideal form. Some participants also described an app or a podcast as a good online form. *"A podcast could be very helpful to listen for listening to experiences of other patients and healthcare providers" (respondent 007).*

Some healthcare providers described experiences of other AYAs to be a necessary element of the information material for AYAs. One doctor also mentioned the power of a film, in which AYAs recognize their own disease process. Finally, reliable sources for any additional information about sexual health and resources for specialized support(sexologist, psychologist, relationship therapist) were identified as useful in the attempt to provide the ideal information package.

Discussion

In this study, we aimed to gain insight into perspectives and best practices of healthcare providers with regard to ideal way of discussing sexual health with AYAs, and their view on providing written information . According to most healthcare providers, discussing sexual health is a shared responsibility of doctors and nurses. There was, however, no overall consensus on the preferred timing. Participants highlighted the importance of offering information at various times and suggested education for the healthcare providers, multidisciplinary approach and communication tools as facilitating factors to enhance the discussion of sexual health with the AYA. A self-report questionnaire for the patients, material to hand out and a checklist for healthcare providers were mentioned as facilitating tools. According to the participants, information material should at least be available online and include personalized information about sexual side effects, do's and don'ts and practical tips.

In concordance with earlier literature on adult oncology, participants in the current study allocated the responsibility for discussing sexual health to both nurses and doctors(19, 30, 31). The importance of clearly defined roles within the medical team was highlighted. A qualitative study conducted by de Vocht et al. slightly supports this by showing that a complementary team approach, with clearly defined roles for different team members is required to improve communication about sexual health in cancer and palliative care. In this model, some members of the oncology team, most likely the oncologist, discuss the sexual side-effects of treatment and check whether patients need help during treatment to identify problems. Other members, most probably nurses, with some affinity with sexual health, have the role of supporting patients with their sexual health issues. Additional training and education could be provided to these members to improve their expertise(3).

In the current study, opinions differed about the optimal timing for discussing sexual health. Some participants preferred to at least address the topic when the initial treatment plan was discussed. We did not find literature about the opinion of AYA healthcare providers or of the AYAs themselves on best timing. It is known to be preference for discussing fertility at the start of treatment(18). AYAs reported limited conversations with healthcare providers about sexual health(15). An online questionnaire study among 667 female breast cancer (ex)patients emphasized the importance of appropriate timing for providing information about sexual health; these patients preferred to at least receive the information shortly after the treatment. Similar to our study, the importance of repetition of the information was mentioned(32). This is also emphasized by AYAs, as they point out the difficulty in remembering the content of the conversations at the start of treatment and their request for ongoing communication throughout treatment and survivorship(15). However, if the impact of treatment on sexual health is considered to be a side-effect of treatment, this should possibly be explained when requiring informed consent. Informed consent is seen as an important part of medical practice and patients‘ autonomy(23). Lack of clarity about sexual side-effects in existing guidelines may result in ambiguity regarding responsibility and timing for discussing sexual health(3).

Sexual health is known to be an important but difficult topic to discuss. In our study some facilitating factors to enhance the discussion have been described. First, in concordance with existing literature, participants emphasized the need for education for healthcare providers(15, 18). This might contain basic and practical knowledge on sexual health implemented in an early stage of an oncologist’s or nurse’s training(18). It would also help healthcare providers to overcome frequently reported barriers, such as lack of knowledge and discomfort and thus falling in line with the AYAs’ reported need for information about potential sexual side-effects(15, 18). A guideline for healthcare providers about sexual side-effects in AYAs would also be useful. Participants in this study describe that it would be easier to initiate the conversation when having a multidisciplinary team meeting about sexual health issues and adequate referral options within their hospital. This is important as AYAs look for support and think the healthcare providers should initiate the conversation about sexual health (15).

Driven by the argument of discomfort, both the AYA and healthcare provider prefer this sensitive topic to be discussed without parents or family. AYAs suggested routinely asking parents or family to step out of the room for the sensitive part of the visits to the clinic(15, 18). Some participants in our study suggested the use of humor as a strategy for rising the topic of sexual health. One should, however, be careful as the use of humor can be perceived as facilitating a discussion but also as derailing.

It is known that in cancer care, the request made by each AYA differ; this is also true for sexual healthcare. Therefore it is important to adjust the care to the individual patient(15). A self-report questionnaire, mentioned in the current study as a tool, might be helpful in clarifying individual needs of the AYA, an thus recognize problems at an early stage. Since conversation time is limited and sometimes AYAs don’t dare initiate the subject, it this might be a helpful tool(18). Furthermore, the importance of addressing sexual problems as a matter of routine in AYA cancer care has been reported(11).

As well as face-to-face conversations with healthcare providers, AYAs report a need for resources(15, 18). Healthcare providers in our study contributed some ideas about content and form of information provision. According to them, the material should at least be adjusted to the type and stage of different forms of cancer, so that it becomes more patient-centered.

Limitations

This study was a nation-wide survey in collaboration with the national AYA-healthcare network. It does have certain limitations. First of all, the sample size was small and most participants were female. However, data saturation was reached with our number of participants and the male-female-ratio is a reflection of the ratio in the Netherlands. Secondly, allied healthcare providers like sexologists were not included; this might affect the results. In the Netherlands, AYAs do not have an appointment with a sexologist as a matter of routine. Only those AYAs with sex related problems, if recognized as such, will be referred to allied healthcare providers. In future studies, it might be relevant to explore the perspective of sexologists and psychologist to formulate more best practices for discussing sexual health. Finally, selection bias may have occurred. Healthcare providers who agreed to participate in this study may have more affinity with this subject. It could be that the perspective of the healthcare provider with less affinity for this subject are underexposed. However, as described before, it is more important to allocate responsibility for discussing sexual health within the team rather than expecting everyone to address the topic in depth.

Conclusion

Cancer can interfere with sexual development of the AYA and may cause problems with sexual health. Sexual health is an important quality-of-life concern; problems with sexual health may negatively affect the quality of life of AYAs(7, 11). This study described the view of the healthcare provider on best practices to meet AYAs' needs regarding sexual health. To facilitate discussing sexual health, clearly defined responsibilities within the team are important. Additionally, sufficient education and the opportunity to discuss sexual concerns in a multidisciplinary meeting are major facilitators for enhancing healthcare providers' knowledge. Self-report questionnaires for the patients, material to hand out and a checklist for healthcare providers could be helpful tools to facilitate discussion. Communication strategies for discussing sexual health are actively initiating a discussion, finding the right moment, normalization of the subject, actively returning to the subject, careful use of humor and ensuring privacy. After all, participation of the AYAs in prioritizing their own care according to their needs for sexual health is crucial.

REFERENCES

1. Cleary V, Hegarty J. Understanding sexuality in women with gynaecological cancer. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2011;15(1):38-45.
2. Woods NF. Toward a holistic perspective of human sexuality: alterations in sexual health and nursing diagnoses. Holistic nursing practice. 1987;1(4):1-11.
3. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9.
4. Zebrack BJ. Psychological, social, and behavioral issues for young adults with cancer. Cancer. 2011;117(10 Suppl):2289-94.
5. Levin NJ, Zebrack B, Cole SW. Psychosocial issues for adolescent and young adult cancer patients in a global context: A forward-looking approach. Pediatric blood & cancer. 2019;66(8):e27789.
6. Wettergren L, Kent EE, Mitchell SA, Zebrack B, Lynch CF, Rubenstein MB, et al. Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study. Psycho-oncology. 2017;26(10):1632-9.
7. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405.
8. Olsson M, Steineck G, Enskar K, Wilderang U, Jarfelt M. Sexual function in adolescent and young adult cancer survivors-a population-based study. Journal of cancer survivorship : research and practice. 2018;12(4):450-9.
9. Stinson JN, Jibb LA, Greenberg M, Barrera M, Luca S, White ME, et al. A Qualitative Study of the Impact of Cancer on Romantic Relationships, Sexual Relationships, and Fertility: Perspectives of Canadian Adolescents and Parents During and After Treatment. Journal of adolescent and young adult oncology. 2015;4(2):84-90.
10. Moules NJ, Estefan A, Laing CM, Schulte F, Guilcher GMT, Field JC, et al. "A Tribe Apart": Sexuality and Cancer in Adolescence. Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses. 2017;34(4):295-308.
11. Mutsch J, Friedrich M, Leuteritz K, Sender A, Geue K, Hilbert A, et al. Sexuality and cancer in adolescents and young adults - a comparison between reproductive cancer patients and patients with non-reproductive cancer. BMC Cancer. 2019;19(1):828.
12. Geue K, Schmidt R, Sender A, Sauter S, Friedrich M. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. Psycho-oncology. 2015;24(11):1368-76.
13. Robinson L, Miedema B, Easley J. Young adult cancer survivors and the challenges of intimacy. Journal of psychosocial oncology. 2014;32(4):447-62.
14. Kirchhoff AC, Fowler B, Warner EL, Pannier ST, Fair D, Spraker-Perlman H, et al. Supporting Adolescents and Young Adults with Cancer: Oncology Provider Perceptions of Adolescent and Young Adult Unmet Needs. Journal of adolescent and young adult oncology. 2017;6(4):519-23.
15. Frederick NN, Revette A, Michaud A, Bober SL. A qualitative study of sexual and reproductive health communication with adolescent and young adult oncology patients. Pediatric blood & cancer. 2019;66(6):e27673.
16. Wang Y, Chen L, Ruan JY, Cheung WY. Discussions about reproductive and sexual health among young adult survivors of cancer. Cancer Med. 2016;5(6):1037-46.
17. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(2):135-45.
18. Frederick NN, Campbell K, Kenney LB, Moss K, Speckhart A, Bober SL. Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians

and adolescent and young adult patients: The clinician perspective. Pediatric blood & cancer. 2018;65(8):e27087.
19. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
20. Albers LF, Haj Mohammad SF, Husson O, Putter H, Pelger RCM, Elzevier HW, et al. Exploring Communication About Intimacy and Sexuality: What Are the Preferences of Adolescents and Young Adults with Cancer and Their Health Care Professionals? Journal of adolescent and young adult oncology. 2019.
21. Depke JL, Onitilo AA. Sexual health assessment and counseling: oncology nurses' perceptions, practices, and perceived barriers. The Journal of community and supportive oncology. 2015;13(12):442-3.
22. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe E. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2019;27(3):887-94.
23. Vadaparampil ST, Gwede CK, Meade C, Kelvin J, Reich RR, Reinecke J, et al. ENRICH: A promising oncology nurse training program to implement ASCO clinical practice guidelines on fertility for AYA cancer patients. Patient education and counseling. 2016;99(11):1907-10.
24. Benedict C, Shuk E, Ford JS. Fertility Issues in Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(1):48-57.
25. Lambertini M, Del Mastro L, Pescio MC, Andersen CY, Azim HA, Jr., Peccatori FA, et al. Cancer and fertility preservation: international recommendations from an expert meeting. BMC medicine. 2016;14:1.
26. Aubin S, Perez S. The Clinician's Toolbox: Assessing the Sexual Impacts of Cancer on Adolescents and Young Adults with Cancer (AYAC). Sex Med. 2015;3(3):198-212.
27. Baarda B BE, Fischer T, Julsing M, Peters V, van der Velden T, Boullart A. Basisboek Kwalitatief onderzoek. Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek. Groningen: Noordhoff Uitgevers; 2018.
28. Olsen PR SS. Nursing Adolescents and Young Adults with Cancer. Developing Knowledge, Competence and Best Practice: Springer; 2018.
29. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.
30. Krouwel EM, Albers LF, Nicolai MPJ, Putter H, Osanto S, Pelger RCM, et al. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
31. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
32. Den Ouden MEM, Pelgrum-Keurhorst MN, Uitdehaag MJ, De Vocht HM. Intimacy and sexuality in women with breast cancer: professional guidance needed. Breast Cancer. 2018.

PART IV

THE ORGANIZATION

Chapter 9: Can the provision of sexual healthcare for oncology patients be improved? A literature review of educational interventions for healthcare professionals

Albers LF, Grondhuis Palacios LA, Pelger RCM, Elzevier HW

Journal of Cancer Survivorship 2020 Dec;14(6):858-866.

Introduction

Sexual health is an important quality-of-life issue in cancer patients and survivors. The negative effect of cancer and its treatment on sexual health is widely described in the literature(1-12). Sexual side-effects can affect patients regardless of age, gender or cancer site. All treatment modalities, surgery, chemotherapy or radiotherapy, cause specific sexual problems and can, therefore, impair sexual health. These problems might arise at the beginning of treatment; it is likely they will continue during long-term follow-up and survival (4, 10, 13-16). Hence, the probability is that all healthcare professionals working with cancer patients will encounter patients who experience sexual problems as a result of their disease or treatment.

Cancer patients and survivors report a need for more information and support regarding sexual health issues (15, 17, 18). They prefer to discuss sexual health with a healthcare professional whom they expect to initiate the topic(13, 19, 20). However, communication about sexual health in oncology care is reported to be challenging(21, 22). Although healthcare professionals do feel a responsibility to discuss the subject, literature reveals that such discussions between patient and professional are limited(13, 21, 23, 24). Healthcare professionals experience various barriers to discussing the subject; those most commonly reported are lack of knowledge and lack of training(21, 25-35). Current literature highlights the need for more training and educational interventions for healthcare professionals to enhance patient-professional communication about sexual health(25, 26, 29-33, 36, 37).

Given these literature recommendations, we aimed to explore which educational interventions for oncology healthcare professionals, designed to enhance the provision of sexual healthcare for oncology patients, have so far been studied and how effective they are. The results of this review could inform the development and implementation of new interventions.

Methods:

This review was performed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Search strategy and outcome:
We conducted a comprehensive literature search in PubMed, PsychInfo, Embase and Emcare with the help of a professional science librarian. The final search included three sets of search items (see appendix 10 for the full search) in the title or abstract linked with "AND", pertaining to (a) oncology (neoplasma, cancer, adenoma, malignancy), (b) sexual health (sexuality, sex counselling, sexual behaviour, sexual dysfunction), (c) education (workshop, training, physicians' discussion).

Eligibility criteria applied for study inclusion are listed in **Table 1**. Studies in which the intervention group was compared to either a control group or baseline were included. We had no time restriction since no previous review of this topic was available. The initial search yielded 1171 studies. First, titles and abstracts were screened for eligibility criteria by two authors (LA and LG). If the article was selected, the full text was screened. Consensus discussions involved a third author (HE) if doubts about inclusion existed.

After screening for title and abstract, 16 full-text articles were assessed for eligibility. Finally, 7 studies were included in the review (See flow diagram in **Figure 1**).

Table 1: Eligibility criteria for inclusion of studies

Items	**Eligibility criteria**
Participant	All healthcare providers who work with oncology patients
Study design	Quantitative interventions study
Language	English
Date of search	No limitation
Type of intervention	All educational/training interventions for healthcare providers with the aim of enhancing provision of sexual healthcare to oncology patients
Type of outcome	Studies reported at least one pre-intervention measurement and one a post-intervention measurement

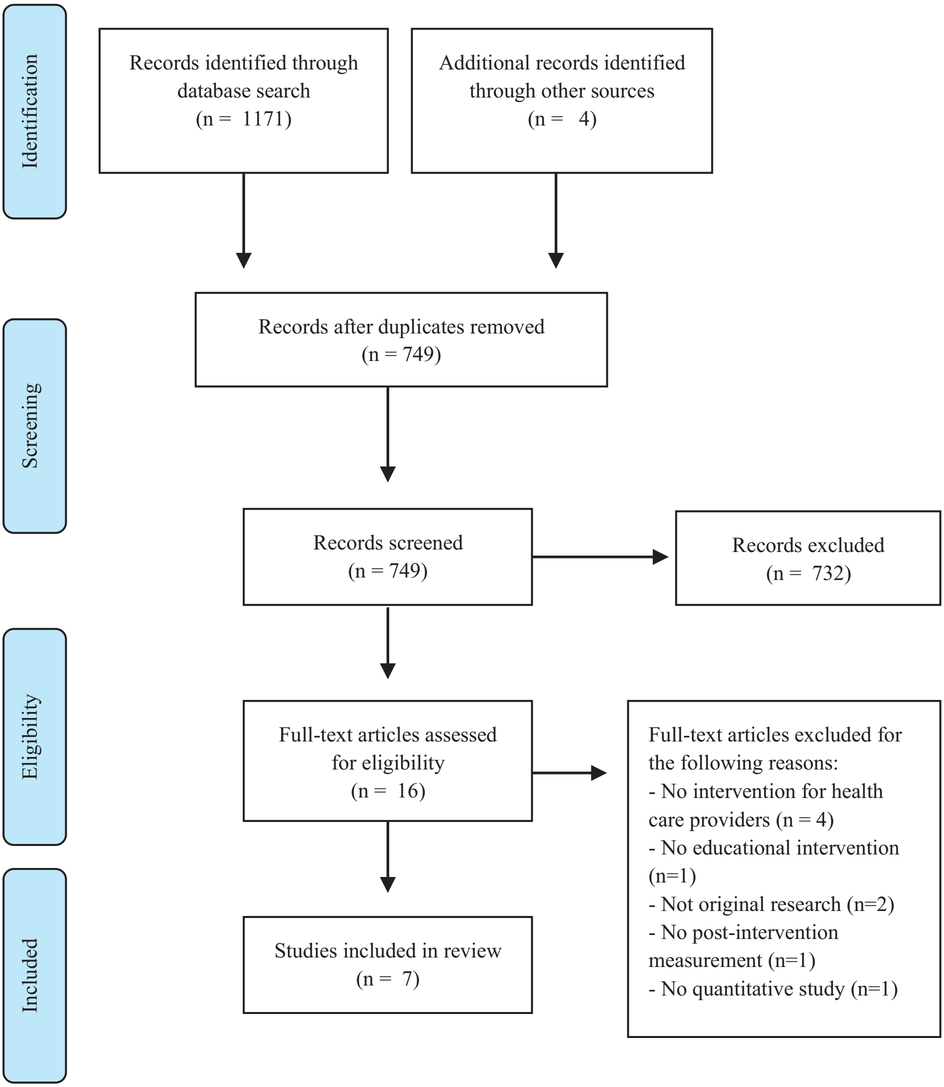


Figure 1: PRISMA Flow Diagram

Level of evidence and quality appraisal
Level of evidence, based on the Oxford Centre for Evidence Based Medicine guidelines, was assigned using the levels of evidence rating system(38), the scale ranging from 1–5. Level 1 represents a meta-analysis of randomized controlled trials (RCT) or a systematic review; level 2 an RCT; level 3 a non -randomized controlled cohort/follow-up study; level 4 a case-series, case-control, or historically controlled studies; level 5 a mechanism-based reasoning.

The Joanna Briggs Institute Critical Appraisal tools were used for quality appraisal of the studies (see Appendix 11).

Two reviewers (LA and LG) scored the studies independently. If no consensus was reached, a third reviewer (HE) was involved. No study was excluded on the basis of the assessment.

Data abstraction
Data was extracted by the first author using a standardized coding sheet (**Tables 2 and 3**), and verified for correctness by a second author (LG).

Table 2: Brief overview of studies included

Source	Intervention type	Sample	Patient type	Work setting	Country	Follow-up	End response	Level of evidence
Pre-/post- questionnaire without control group								
Hordern (2009)	Single workshop (4.5h)	155 oncology nurses and allied HCPs	Not specified	Unknown	Australia	Immediately post-workshop, eight weeks	58.6%	3
Wang (2015)	Single training (30-45 min)	9 oncology physicians, 62 nurses/allied HCPs	Breast cancer	Suburban, four-hospital health-care system	USA	Three-six months	50%	3
Afiyanti (2016)	Five days' training (35h)	46 oncology nurses	Not specified	Hospitals specialized in cancer services	Indonesia	Three weeks	100%	3
Jonsdottir (2016)	Comprehensive long-term educational intervention project (2 years)	210 oncology nurses and physicians	Not specified	University hospital	Iceland	10 months, 16 months	38%	3
Grondhuis (2019)	One symposium (one day)	55 uro-oncology HCPs	Prostate cancer	Various	Holland	Six months	75%	3

Continuation **Table 2**

Source	Intervention type	Sample	Patient type	Work setting	Country	Follow-up	End	Level of evidenc
Pre-/post-questionnaire with randomized control group								
Kim (2014)	Eight e-learning sessions (total 16h, 8 weeks)	31 oncology nurses (15 interventions, 16 controls)	Not specified	Tertiary hospital	Korea	Three months	100%	2
Mixed methods: pre-/Reese (2019)post- questionnaire and audio records								
Reese (2019)	One self-study module (15 min), one workshop (60 min)	5 oncologists, 1 nurse practitioner, 1 physician assistant 134 breast cancer patients	Breast cancer	Cancer center	USA	Healthcare professionals: Direct post-intervention, one month, six months Patients: immediately after the visit	100%	3

Table 3: Overview of the interventions

Jonsdottir (2016)	**Intervention type**	Hospital-wide educational intervention project lasting two years to integrate sexual health into oncology, consisting of: - Identification of a team of 25 ‘ change agents’ who act as role models on their wards - Establishment of a sexuality counselling service for cancer patients - Education and training of staff (40 staff members from 10 different units): two 5h workshops focused on attitudes and practices. Teaching methods applied were lectures, group discussion, taking sexual history. The second workshop focused on more role play exercises to practice communication - Educational meetings between staff and (ward) change agents (20-30 minutes), about communication strategies; practical issues and screening possibilities were discussed - Development of a staff pocket-guide for nurses and physicians as an aid to initiate communication - Development of patient information material - Development of a website about cancer and sexuality for healthcare providers and patients
	Measurement	Self-report questionnaire, enquiring about: practice issues (8, 5-point Likert-scale), attitudes (8, 5-point Likert-scale), frequency of discussing topic (1, multiple choice), barriers (1, multiple choice), responsibility for initiative (1, multiple choice)
	Primary outcomes	- Change in mean scores before the intervention and at 16 months - Knowledge and training (1), practices issues (2), frequency of discussing topic (3), initiative (4), barriers (5)
	Results	(1) Have acquired sufficient knowledge and training; resp. p=0.01, p=0.006 (2) 5/8 practice issues improved; p<0.01 (3) No change in frequency of discussing topic (4) No change in initiative (5) Fewer perceived barriers; p=0.038

Continuation **Table 3**

Kim (2014)	**Intervention type**	- Online problem-based learning (e-PBL); case videos with eight tutorials involving sexual health care problem scenarios; one session presented each week (1-2h). - Posting solutions to the scenarios and discussions with others. - Additional online tools, such as video lectures, chat, discussion forum, databases, external website links were available
	Measurement	Self-report questionnaire containing: ‘Sexual health care knowledge scale’ (33, yes/no), ‘Sexual health care attitude scale’ (17, 3-point Likert scale), ‘Sexual health practice scale‘ (21, yes/no)
	Primary outcomes	- Change in mean change for scores between intervention and control group at 3 months’ follow-up - Knowledge (1), attitude (2), practice (3)
	Results	(1) Higher knowledge score; p=0.04 (2) No change in attitude score (3) No change in practice score
Wang (2015)	**Intervention type**	Single session, face-to-face, targeted sexual health training, 30-45 minutes. Traditional didactic education and communication skills training via brief role play and introduction of a user-friendly sexual health assessment tool
	Measurement	Self-reported questionnaire, enquiring about: comfort level (2, 5-point Likert scale), frequency (6, 5-point Likert scale), access to sexual health resource (1, 5-point Likert scale)
	Primary outcomes	- Changes in mean Likert scores between baseline and 6 months’ follow-up - Comfort level (1), self-reported frequency of addressing sexual issues (2)
	Results	(1) Higher comfort level; p<0.0001 (2) Higher frequency of addressing issues; p<0.0001

Continuation **Table 3**

Reese (2019)	**Intervention type**	**S**ingle session self-study via information workbook (15 min) and single session workshop (90 minutes); skills-based, engagement in the first two steps of PLISSIT framework
	Measurement	Healthcare providers: - Self-reported questionnaire enquiring about: self-efficacy (3, 11-point scale), expected outcome regarding communication (7, 11-point scale), perceived barriers (14, 6-point scale) - Audio recording of clinic encounters Patients: - Satisfaction Index (4, 5-point Likert scale)
	Primary outcomes	Health care professionals: - Changes in mean scores between baseline and 6 months - Self-efficacy (1), outcome expectation (2), perceived barriers (3) - Odds/rate ratio; - Requesting/offering information about sexual health (4), complex issues involved in requesting/offering information (5), raising the topic(6), duration of sexual health communication(7) Patients: - Changes in mean score, between baseline and immediately after the consultation - Satisfaction (8)
	Results	(1) Increased self-efficacy; d=0.27 (2) Increased outcome expectation; d=0.69 (3) Reduced barriers; d= -0.14 (4) Increased frequency of requesting/offering information; OR = 1.66/1.44, respectively (5) Increased complexity; OR=1.65 (6) Increased frequency of raising the topic; OR = 2.38 (7) No change in duration; RR = 1.04 (8) No change in patient satisfaction

Continuation **Table 3**

Grondhuis (2019)	**Intervention type**	One-day symposium with lectures on sexual dysfunction following several types of prostate cancer treatment and two workshops focusing on counselling techniques and tools to address sexual dysfunction in uro-oncological patients
	Measurement	Self-reported questionnaire (different for doctors, nurses/PAs, sexologists), enquiring about: knowledge (5-point Likert scale), discussion of sexual dysfunction (5-point Likert scale), rate of referral (5-point Likert scale), competence (3 polar questions: discussion of sexual function, advising on SD and actively enquiring about sexual issues
	Primary outcomes	- Changes in mean between baseline and six-months' post-intervention - Knowledge (1), competence (2), frequency (3), referral rate (4)
	Results	(1) No change in knowledge; p=0.39 (2) No change in competence; p=0.25 (3) Higher frequency; p<0.01
Afiyanti (2016)	**Intervention type**	Five-day competency-based training, 35 hours in total, consisting of 6 sessions in the classroom or 3 days of lectures and 4 practice sessions. After the training, a 3-week mentorship process
	Measurement	Questionnaire including knowledge test (13 items, each with 5 answer options), and addressing attitudes/belief (14, 5-point Likert scale), self-efficacy (5, 5-point Likert scale), practice (11, 5-point Likert scale)
	Primary outcomes	- Changes in mean between baseline and 3 weeks post-intervention - Knowledge (1), attitude/belief (2), self-efficacy(3), practice(4)
	Results	(1) Higher knowledge score; p<0.001 (2) Higher attitude/belief score; p=0.008 (3) Higher self-efficacy score; p=0.017 (4) No change in practice; p=0.062

Continuation **Table 3**

Hordern (2009)	**Intervention type**	Single session, face-to-face workshop (4.5 hours) with a professionally trained actor in the role of cancer patient to practice communication. The participants received feedback from the group
	Measurement	Self-reported questionnaire, addressing: barriers (20, 5-point Likert scale), confidence (7, 5-point Likert scale), practice (8, 5-point Likert scale)
	Primary outcomes	- Changes in means scores between baseline and eight weeks' follow-up - Barriers(1), confidence (2), practice (3)
	Results	(1) 16/20 barriers decreased; p<0.01 (2) 7/7 confidence issues increased; p<0.001; There were no significant effects of age or work experience on the participants' confidence scores (3) 8/8 practice items increased; p<0.003

Results

Participants

A total of 572 oncology (range 7 – 210) healthcare professionals participated in the seven included studies (**Table 2**). Of these, 556 healthcare professionals participated in an intervention; the other 16 acted as controls in one (39). The participants included 384 nurses and other allied health care professionals, 48 physicians and 9 sexologists. The function of 131 participants, either oncologist or nurse, was not specified(28, 40). Two studies focused specifically on healthcare professionals working with breast cancer patients and one on healthcare professionals working with prostate cancer patients(41-43). The other studies did not specify an area of expertise of the participants.

Design & quality appraisal

One study was a randomized control trial with a control group(39). Six studies had a pre-post-questionnaire design without a control group(28, 40-44). Of these six, one study described additional audio records of consultations between healthcare professional and patients (mixed-methods approach). The audio recording of clinic encounters were transcribed and coded for analysis. In addition, patients completed a questionnaire about the conversation with the healthcare professional immediately after the visit(41). The time of follow-up varied between directly after the intervention and up to 16 months later. All study designs are described in **Table 2**. The quality appraisal showed very similar results in all studies (see appendix 12). The most common weakness was the lack of a control group.

Type of interventions

A detailed overview of the interventions studied is presented in **Table 3**. The interventions used a combination of (video) lectures, symposia group discussions and practical sessions All interventions used in the studies were different and were developed by the authors or institution themselves. The duration of the intervention varied between 30 minutes and a two-year program. Four studies provided the healthcare professionals with a single session intervention (40-43). One study investigated a program of five days(44). Another study investigated hospital-wide multiple interventions over a period of two years(28). Finally, one study evaluated eight online tutorials for a period eight weeks. This was the only fully online intervention(39).

Type of measurement

Self-reported questionnaires were used in all studies to evaluate outcome pre- and post-intervention (28, 39-44). Only Kim et al. used questionnaires which had previously been described in literature and had proved to be valid and reliable (39, 45). The questionnaires used in the other studies were developed by the authors based on social cognitive models, guidelines, previous studies, literature or expert opinion. They contained questions about knowledge, attitude, practice patterns, perceived barriers and comfort level. In addition, one study assessed clinical communication coded from audio recorded conversations, patient satisfaction via a questionnaire and the duration of sexual health communication(41). All measurements are summarized in **Table 3**.

Objectives and results

Most primary objectives were described as the assessment of having acquired sufficient knowledge about sexual health, improvement of practice, frequency of discussing sexual health and comfort level and the decline of perceived barriers to discussing sexual health. All objectives and results are displayed in **Table 3**.

Three studies measured the perception about having acquired sufficient knowledge and training to be able to discuss sexual health(28, 39, 42). Two studies reported a significantly higher self-reported knowledge score after the intervention(28, 39). The interventions in these two studies contained multiple education moments, in contrast to the study without an effect(42). Participants of one study performed a test which assessed their knowledge about sexual health, before and after the intervention. Participants scored significantly higher after the intervention(44).

Four studies measured current practices, such as giving patients oral or written information about sexual health, initiating discussions and referrals to another professional(28, 39, 40, 44). Of these studies, two showed no significant improvement in practice(39, 44). One of these investigated an online intervention with no face-to-face contact(39). The other study had a 35-hour program over a period of five days(44).

The frequency of discussing sexual health was measured in four studies(28, 41-43). In three, the frequency increased. The study which did not find this effect had a longer follow-up time (16 months) compared to the others (6 months)(28).

Three studies described the effect of the intervention on perceived barriers to discussing sexual health, such as lack of time, privacy, difficult topic to discuss, embarrassment, fear patient will react negatively. All showed a significant decrease in perceived barriers(28, 40, 41).

Six studies described a comfort level score for discussing sexual health (e.g. confidence, attitude or self-efficacy level) (39-41, 43, 44). The five studies which showed a significant effect were skill-based interventions(40, 41, 43, 44).

One study assessed the patients’ satisfaction and length of the total consultation(41). Patient satisfaction did not change significantly over time. Nor did the duration of the total conversation . Most sexual health discussions lasted less than 1 minute.

Consent, completion and feedback from the participants
The acceptance rate for participation described in two studies was 50% and 88%(41, 43). Reasons for non-participation were not described. All studies described completion of the intervention and questionnaire. The rate of completion ranged from 38 - 100%(28, 39-44). In terms of acceptability and feasibility of the programs, participants in four studies returned feedback about the intervention(28, 39, 41, 43). Content of the intervention was considered as useful and relevant for the area of practice(28, 43). Two studies described a level of satisfaction with the intervention of 53% and a score of 4.1/5(39, 41).

Discussion

In this systematic review, we identified studies which evaluated educational interventions for oncology healthcare professionals to improve communication about sexual health with patients.

Healthcare professionals may benefit from these educational interventions. These studies found an increase in the number reporting having sufficient knowledge, frequency of discussing, comfort levels and fewer perceived barriers due to an intervention for healthcare professionals. The results should, however, be interpreted with caution given the lack of control groups, small intervention groups, lack of validated questionnaires and absence of long-term follow-up.

We did not expect the studies to be so limited, given the large quantity of publications highlighting the need for education of healthcare professionals due to their frequently reported lack of knowledge and training. Unfortunately, it was not possible to provide an overall recommendation because of the heterogeneity of the data. The interventions, measurement, follow-up duration and outcomes were different in the included studies. Moreover, the most common weaknesses in the study design were the lack of a control group and the lack of long-term follow-up. As a result, long-term effect of the interventions is unknown. There is no indication on how frequently the interventions should be repeated for an optimal result.

The relationship between education and practice performance of clinicians has been widely studied. A review about this subject stated that "live, face-to-face educational activities are effective, especially when combined with multiple exposures to the information following the live educational activity(46)." Besides, multiple educational techniques have a greater long-term effect on practice performance than a single technique. Multiple exposures also have a favourable effect on the performance(46). Against this background, the comprehensive long-term education program of Jonsdottir et al. meets this conditions(28). Still, no changes were found in frequency of discussing sexual health or in taking the initiative to discuss the topic, between baseline and 16 months' follow-up. This might be due to barriers perceived by the healthcare professionals or the fact that not all healthcare professionals might want to become an expert in discussing sexual health.

In our review, studies with face-to-face, skill-based interventions, for example a role play exercise during a workshop, showed a significant increase in comfort level of the participants to approach a discussion. Practicing during the interventions gives the participants the opportunity to apply their skills in a safe environment. The only online learning intervention did not show an increase in comfort level(39). One might argue that face-to-face education with practice exercises is more effective for a taboo subject such as sexual health in overcoming feelings of shame, a frequently reported barrier to discussing sexual health with patients(26, 29, 32). Also, a qualitative study which focused on feedback about an educational intervention designed to enhance communication about sexual health, described that a role-play exercise boosts the courage of the participants to initiate conversation(47). However, face-to-face interventions are mostly time-consuming. Time is an important consideration when developing a new intervention for healthcare professionals, as lack of time is already a barrier to discussing sexual health. The study by Wang et al. described a face-to-face, targeted, single sexual health training lasting 30-45 minutes(43). Both comfort level and frequency of addressing the topic were increased after six months follow-up, indicating a brief training might be sufficient. This result should, however, be interpreted with caution as it was a pilot study with a small number of participants and a high attrition rate.

Thus, in order to integrate sexual healthcare into medical practice, more is needed than education for individual oncology healthcare professionals. Financial aspects and organizational factors, like clinical space and agreement that healthcare professionals will devote time to providing sexual healthcare, are also important(48). Current literature lacks proof of the optimal format of sexual health in oncology care. A few studies investigated interventions, other than educational, to enhance sexual healthcare. A prospective observational cohort study assessed the impact of a screening tool, the 'Brief Sexual Symptom Checklist for Women', used by oncology healthcare professionals, on the referral rates to allied healthcare professionals, like sexual counsellor or psychologist. No significant difference in referral was found. Moreover, more than half of the patients failed to attend sexual counselling following referral by their specialist(49). The effectiveness of a nursing record focused on sexual health care was tested among oncology nurses in a randomized control trial(50). The record was based on the PLISSIT model, commonly used for clinicians to discuss sexual health. The use of the record had a significant effect on the sexual healthcare practice of nurses compared to the control group. There was, however, no difference in sexual healthcare attitude score (discomfort, feeling uncertain), which might indicate the need for additional skill-based training.

Another study which investigated a multidisciplinary sexual health program implemented in their hospital faced different challenges, like lack of funding, lack of staff and excessive waiting times due to heavy use of the clinic(48, 51). They found that basic resources were lacking; patients were not having their sexual health concerns addressed elsewhere during their treatment process(48). They highlight the need for oncology healthcare professionals to address sexual health proactively and thus reduce referral to the program. The need for support from the department of Nursing and an inter-professional team approach were highlighted as important issues by these studies(48, 51). A network of representatives from different departments, like psychiatry, social work and urology is needed to assist with cases as required. They do not actually have to attend the sexual healthcare clinic in person but should be available for consultation if required(51).

Some limitations need to be considered. Only seven studies were included in this review. Most studies were small and did not have a control group. Selection bias may have occurred as in six studies the participants were not randomized. Moreover, the recruitment of participants was by self-selection or not adequately described in most studies. Response bias may have occurred in some studies due to attrition rates. It is likely that the most motivated participants completed the follow-up.

The long-term effect of the educational programs is not known since only short-term follow-up was described in the studies. Due to the different outcome measurements used, it was not possible to provide an overall recommendation. To improve the comparison of future studies, it would be helpful if validated questionnaires were routinely used and a control group included. It is recommended that future studies are longitudinal in order to access the learning effect and practice over time. It would be interesting to include non-educational intervention to find out whether other factors can also contribute to enhancement of sexual healthcare for oncology patients. In this context, including patient-reported data about patient satisfaction and duration of sexual health communication would be helpful to demonstrate that an improvement in the effect of interventions translates into improved patient satisfaction and quality of life(41).

Conclusion

Sexual health is an important area of cancer survivorship. There is a demand for sexual healthcare by the oncology patients but many oncology healthcare professionals lack training and knowledge to provide such care. This systematic review provides an insight into the existing interventions and education of oncology healthcare professionals and might be helpful for the development of new interventions and studies. An overall recommendation for the development of interventions could not be given due to the limited number of studies and heterogeneity of the data. Notwithstanding, one could argue that following the interventions, healthcare professionals become more aware of the importance of addressing sexual health. More evidence based practices are needed.

REFERENCES

1. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405.
2. Aerts L, Christiaens MR, Enzlin P, Neven P, Amant F. Sexual functioning in women after mastectomy versus breast conserving therapy for early-stage breast cancer: a prospective controlled study. Breast (Edinburgh, Scotland). 2014;23(5):629-36.
3. Albaugh JA, Sufrin N, Lapin BR, Petkewicz J, Tenfelde S. Life after prostate cancer treatment: a mixed methods study of the experiences of men with sexual dysfunction and their partners. BMC urology. 2017;17(1):45.
4. Almont T, Bouhnik AD, Ben Charif A, Bendiane MK, Couteau C, Manceau C, et al. Sexual Health Problems and Discussion in Colorectal Cancer Patients Two Years After Diagnosis: A National Cross-Sectional Study. The journal of sexual medicine. 2019;16(1):96-110.
5. Almont T, Couteau C, Etienne H, Bondil P, Guimbaud R, Schover L, et al. Sexual health and needs for sexology care in digestive cancer patients undergoing chemotherapy: a 4-month cross-sectional study in a French University Hospital. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018.
6. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. Journal of cancer survivorship : research and practice. 2016;10(3):600-9.
7. Dizon DS, Suzin D, McIlvenna S. Sexual health as a survivorship issue for female cancer survivors. The oncologist. 2014;19(2):202-10.
8. Farthmann J, Hanjalic-Beck A, Veit J, Rautenberg B, Stickeler E, Erbes T, et al. The impact of chemotherapy for breast cancer on sexual function and health-related quality of life. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2016;24(6):2603-9.
9. Gilbert E, Ussher JM, Hawkins Y. Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. Health (London, England : 1997). 2009;13(5):523-41.
10. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer nursing. 2009;32(4):271-80.
11. Kedde H, van de Wiel HB, Weijmar Schultz WC, Wijsen C. Sexual dysfunction in young women with breast cancer. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2013;21(1):271-80.
12. Twitchell DK, Wittmann DA, Hotaling JM, Pastuszak AW. Psychological Impacts of Male Sexual Dysfunction in Pelvic Cancer Survivorship. Sexual medicine reviews. 2019.
13. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94.
14. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2012;30(30):3712-9.
15. Stabile C, Goldfarb S, Baser RE, Goldfrank DJ, Abu-Rustum NR, Barakat RR, et al. Sexual health needs and educational intervention preferences for women with cancer. Breast cancer research and treatment. 2017;165(1):77-84.
16. Sadovsky R, Basson R, Krychman M, Morales AM, Schover L, Wang R, et al. Cancer and sexual problems. The journal of sexual medicine. 2010;7(1 Pt 2):349-73.
17. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.
18. Hautamaki-Lamminen K, Lipiainen L, Beaver K, Lehto J, Kellokumpu-Lehtinen PL. Identifying cancer patients with greater need for information about sexual issues. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2013;17(1):9-15.

19. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.
20. Reese JB, Sorice K, Lepore SJ, Daly MB, Tulsky JA, Beach MC. Patient-clinician communication about sexual health in breast cancer: A mixed-methods analysis of clinic dialogue. Patient education and counseling. 2019;102(3):436-42.
21. Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. British journal of cancer. 2003;88(5):666-71.
22. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: How frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
23. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
24. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
25. Adams E, Hill E, Watson E. Fertility preservation in cancer survivors: a national survey of oncologists' current knowledge, practice and attitudes. British journal of cancer. 2013;108(8):1602-15.
26. Depke JL, Onitilo AA. Sexual health assessment and counseling: oncology nurses' perceptions, practices, and perceived barriers. The Journal of community and supportive oncology. 2015;13(12):442-3.
27. Frederick NN, Campbell K, Kenney LB, Moss K, Speckhart A, Bober SL. Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians and adolescent and young adult patients: The clinician perspective. Pediatric blood & cancer. 2018;65(8):e27087.
28. Jonsdottir JI, Zoega S, Saevarsdottir T, Sverrisdottir A, Thorsdottir T, Einarsson GV, et al. Changes in attitudes, practices and barriers among oncology health care professionals regarding sexual health care: Outcomes from a 2-year educational intervention at a University Hospital. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2016;21:24-30.
29. Krouwel EM, Albers LF, Nicolai MPJ, Putter H, Osanto S, Pelger RCM, et al. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
30. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
31. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.
32. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
33. Reese JB, Beach MC, Smith KC, Bantug ET, Casale KE, Porter LS, et al. Effective patient-provider communication about sexual concerns in breast cancer: a qualitative study. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2017;25(10):3199-207.

34. Schouten B, Bergs J, Vankrunkelsven P, Hellings J. Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study. European journal of cancer care. 2019;28(1):e12936.
35. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe E. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2019;27(3):887-94.
36. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.
37. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.
38. Oxford levels of evidence based medicine. Centre for Evidence Based Medicine. Available from: www.cebm.net.
39. Kim JH, Shin JS. Effects of an online problem-based learning program on sexual health care competencies among oncology nurses: a pilot study. Journal of continuing education in nursing. 2014;45(9):393-401.
40. Hordern A GM, Hegarty S, Jefford M, White V, Sutherland G. Discussing sexuality in the clinical setting: The impact of a brief training program for oncology health professionals to enhance communication about sexuality. Asia-Pacific Journal of Clinical Oncology. 2009;5:270-7.
41. Reese JB, Lepore SJ, Daly MB, Handorf E, Sorice KA, Porter LS, et al. A brief intervention to enhance breast cancer clinicians' communication about sexual health: Feasibility, acceptability, and preliminary outcomes. Psycho-oncology. 2019;28(4):872-9.
42. Grondhuis Palacios LA, Hendriks N, den Ouden MEM, Reisman Y, Beck JJH, den Oudsten BL, et al. Investigating the effect of a symposium on sexual health care in prostate cancer among Dutch healthcare professionals. J Clin Nurs. 2019.
43. Wang LY, Pierdomenico A, Lefkowitz A, Brandt R. Female Sexual Health Training for Oncology Providers: New Applications. Sexual medicine. 2015;3(3):189-97.
44. Afiyati Y KB, Ruwaida I, Rachmawati I, Agustini N. Improving quality of life on cancer patient by implementation of psychosexual health care Jurnal Ners. 2016;11(1):7-16.
45. Kim S, Kang HS, Kim J-H. A sexual health care attitude scale for nurses: Development and psychometric evaluation. International Journal of Nursing Studies. 2011;48(12):1522-32.
46. Davis D, Galbraith R. Continuing medical education effect on practice performance: effectiveness of continuing medical education: American College of Chest Physicians Evidence-Based Educational Guidelines. Chest. 2009;135(3 Suppl):42s-8s.
47. Winterling J, Lampic C, Wettergren L. Fex-Talk: a Short Educational Intervention Intended to Enhance Nurses' Readiness to Discuss Fertility and Sexuality with Cancer Patients. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
48. Duimering A, Walker LM, Turner J, Andrews-Lepine E, Driga A, Ayume A, et al. Quality improvement in sexual health care for oncology patients: a Canadian multidisciplinary clinic experience. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2019.
49. Roberts K, Chong T, Hollands E, Tan J, Mohan G, Cohen PA. Screening for sexual health concerns in survivors of gynecological cancer. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2019.
50. Jung D, Kim JH. Effects of a sexual health care nursing record on the attitudes and practice of oncology nurses. Sexual & reproductive healthcare : official journal of the Swedish Association of Midwives. 2016;9:21-6.
51. Barbera L, Fitch M, Adams L, Doyle C, Dasgupta T, Blake J. Improving care for women after gynecological cancer: the development of a sexuality clinic. Menopause (New York, NY). 2011;18(12):1327-33.

PART V

FUTURE DIRECTIONS

Chapter 10: Summary and general discussion

The main purpose of this thesis was (1) to evaluate the needs and preferences of information and support regarding sexual health in cancer care and (2) to investigate the best way of providing information regarding sexuality to patients. In addition, (3) strategies to enhance communication about sexuality were explored.

Over the last decades, it has been well studied that cancer and its treatment have a negative impact on sexuality and intimacy of patients with cancer and their partners. A negative impact on sexuality might occur regardless of age, cancer type or treatment(1). Problems with sexuality might arise at time of diagnosis, during treatment or follow-up. Sexual health problems are likely to remain into long-term survivorship(1-5). Patients do report a need for information and support with these problems(6-13). However, patients, as well as healthcare providers, experience several barriers to discuss sexual health in medical practice. This thesis adds new insights about preferences of patients and partners regarding information and support for cancer induced sexual concerns (**Chapter 2, 4, 5, 7)**. Additionally, in **Chapter 3** factors which are related to sexual satisfaction after cancer treatment were discussed, in particular for patients after radical prostatectomy for prostate cancer. In **Chapter 6, 7** and **8** perspectives of healthcare professionals were described. **Chapter 9** provided insights in the effectiveness of education for healthcare professionals to enhance communication about sexuality and describes other factors to optimize the delivery of sexual healthcare. Finally, a summary of the results and future directions are described in this chapter (**Chapter 10).**

The patient

Not all patients with cancer may have the same need for information regarding sexual health(14). According to the survey described in **Chapter 2**, 35% of the cancer patient did not report a direct need for information. To deliver patient-centered care, it would be helpful to explore which patients are more in need of information. In **Chapter 2** was found that younger age, more self-reported negative impact of cancer on sexuality and time since diagnosis were associated with a higher need. These factors can be seen as guiding factors, not to exclude patients from information or support. Younger patients, for example, reported a higher information need. However, sexual activity continues to an old age. Older adults stated their sexual life as important. Therefore, sexuality in older patients cannot be neglected (1, 6, 15-18). Though research in the elderly cancer patient is limited. In **Chapter 2,** a higher need for support and information was found in patients diagnosed less than two years ago. This finding may indicate that information should be provided actively to patients during this period. In **Chapter 5,** investigating the preferences of breast cancer patients, was again highlighted that information should be offered at the appropriate time during the treatment process. AYAs (**Chapter 7)** agreed with the importance of timing of information, preferably at start of treatment. Timely information provision may contribute to realistic expectations of the impact of cancer treatment on sexuality and may reduce distress(21). Nevertheless, in **Chapter 2** was described that 57% of the respondents who were diagnosed with cancer more than 10 years ago still reported a need for information. This indicates the importance of the availability of information regarding sexuality during long time follow-up. Sexual issues are known to remain into long-term survivorship(2). It is recommended to embed information regarding sexuality not only in standard care and follow-up but also make it is available and easily accessible online without healthcare professionals needing to be the gatekeepers to that information.

Chapter 2 further explored what kind of information cancer patients preferred. Practical advice, practical information and experiences from others were considered as most useful. **Chapter 7** and **Chapter 5** suggested that information can be offered during a conversation with a healthcare professional as well as in written form via brochures or websites. Given the distribution of preferences regarding kind of information, the availability of information in multiple forms would be helpful. In **Chapter 7** and **Chapter 5** most patients reported to feel most comfortable to discuss sexuality with a nurse practitioner. In the Netherlands, the nurse practitioner plays a coordination role in cancer care and supports patients during treatment and follow up. Previous research reveals that nurses do feel responsible for discussing treatment related sexual problems with patients, but experience some barriers to discuss sexual health(19, 20). There is ongoing research to develop interventions which try to support healthcare providers.

Chapter 3 demonstrated that sexual satisfaction of prostate cancer patients is not exclusively dependent on erectile function. Sexual satisfaction before cancer treatment is more important to sexual satisfaction than the erectile function itself. Moreover, no improvement nor decrease in sexual satisfaction between 6-months and 36-months follow-up in patients with erectile dysfunction were found. Psychological interventions focusing on adjustment to changes in sexual functioning after surgery might improve sexual satisfaction; especially for those men who remain suffering from erectile dysfunction(21). It can be argued that these findings might also be true for other cancer types. In a study among survivors of testicular cancer (TC) and their spouses was found that older TC survivors had a greater sexual satisfaction, although a younger age was predicted a better sexual functioning in TC survivors. Sexual satisfaction was strongly related to marital satisfaction(22). This supports our findings that sexual satisfaction and sexual function are not perfectly matched. It is recommended not only to ask about sexual function but also about sexual satisfaction and relationship to deliver good sexual healthcare. More research is needed to implement and optimize this care.

The partner

Previous literature revealed that partners of patients with cancer report a negative impact on their sexuality and relationship due to disease and treatment(7, 23-27). In **Chapter 4** and **Chapter 5**, partners reported the need to be involved in communication and information regarding sexual health. These chapters further investigated which partners are more in need as well as their preferences. In contrast to the findings in **Chapter 2** and the existing literature, in **Chapter 4** (a survey among partners of patients with cancer) was found that age and time since diagnosis were not associated with a higher need for information(6, 7, 18). Patients' treatment or stage of disease were neither related. In concordance with findings in **Chapter 2**, self-reported negative impact of cancer on sexuality and intimacy was associated with a higher information need. Given these findings, it might be difficult to identify partners who are likely to be more in need of information. Moreover, it can be argued that partners are less likely to directly report their need for support and information regarding treatment induced sexuality problems. Some partners may consider their sexual needs are inappropriate(24). In time, people want life to return to as normal as possible again and may have more attention for sexuality and intimacy. During this phase, information regarding sexual health might be more important. Though, partners in **Chapter 5** reported to prefer to receive information regarding sexual health before treatment. Suitable information with respect to sexuality and intimacy for partners can be helpful to create realistic expectations about sexual function during treatment and after cancer(28). Additionally, open communication may result in better coping with sexual concerns(29-31). Partners in **Chapter 4**, suggest that information should be easily accessible and actively provided to partners. To optimize information and support, future research could include a longitudinal prospective study to evaluate information for partners per type of cancer including qualitative data.

The healthcare professional

As described in **Chapter 2, 4, 5** and **7**, in current medical practice, communication about treatment induced sexual concerns between patient, partners and healthcare professional is not routine of care. Literature reveals several difficulties and mismatches in expectations in discussing sexual health in cancer care(7, 8, 16, 24, 32). Best timing of providing information and the responsibility for discussing sexual side effects within a medical team was point of discussion. Regarding best timing, healthcare professionals working with AYAs (**Chapter 8)** tended to discuss more urgent side effects of cancer treatment first. Some did consider sexual side effects not as a priority. Further, in **Chapter 6,** Dutch oncologists stated to rarely bring up sexual side-effects during the informed consent conversation before the start of treatment. Informed consent is seen as a crucial component of medical practice and authenticates patients‘ autonomy(23). Given the high prevalence and additional burden of sexual dysfunction after cancer treatment, these sexual side-effects of treatment may considered to be part of informed consent conversation(1, 33-38). Lack of clarity about sexual side-effects in existing guidelines may result in ambiguity regarding timing for discussing sexual health(39).

Concerning the responsibility of bringing up the subject, members of the multidisciplinary oncological team seem to count on each other to tackle the conversation about sexual health(19, 20, 40). **Chapter 6** and **8** emphasized the importance of defining responsibilities within the oncology treatment team. De Vocht et al. described a Stepped-Skills-model, which could be of help to define responsibilities(39). In this team-approach-model, there are team members who are “spotters”. These spotters, most likely the oncologist, discuss sexual side-effects of treatment, check whether patients need help and refer them when necessary. Other members are called “skilled companions”. They have the responsibility to support patients in their sexuality issues. This task fits probably best to specialized nurses given their frequent contact with the patient and their available time, as reported in **Chapter 8.** Consequently, these members require training to improve their communication skills and their knowledge.

As facilitating tools to enhance communication about sexual health in medical practice, healthcare professionals, interviewed in **Chapter 8,** suggested a self-report questionnaire for the patients, a checklist for healthcare professionals and material to hand. The availability of written material was also emphasized by the patients who participated in the surveys in **Chapter 2, 5** and **7**. However, with the increasing pressure on daily practice of healthcare professionals, and taking the major barrier – lack of time - into consideration, there is also a need for alternative ways of providing sexual healthcare.

The organization & future directions

There has been a call within cancer care organizations to improve patient reported outcomes by improving the delivery of sexual healthcare for cancer patients. Suitable sexual healthcare includes psychosocial support, attention for the partner and information about treatment options(41). Current literature is lacking an optimal format of sexual health in oncology care. However, some models of providing sexual healthcare are described in literature(42, 43). These models are described as a pyramid of care; at the bottom general, straight-forward services that are of benefit for all patients. Services more toward the top are more intensive and specialized, for complex problems (**Figure 1**). For a part of the patients, and partners, queries can be solved with (online) educational materials only, as displayed in the bottom of the pyramid in **Figure 1**(43). Others may in need of a step up in the pyramid and prefer to discuss the topic with a healthcare professional. However, in concordance with previous research, the survey among oncologist in **Chapter 6** reported important reasons for the lack of frequency in discussing sexual health to be a 'lack of training' and a 'lack of knowledge'(19, 20, 40, 44). Education for healthcare professionals is highlighted in **Figure 1,** as well as in **Chapter 8** and **Chapter 6** of this thesis. **Chapter 9** focussed on the effectiveness of educational interventions for oncology healthcare professionals to improve communication about sexual health with patients. The amount of studies and quality were limited. Therefore an overall recommendation could not be provided. Nevertheless, an increase in having enough knowledge, practice items, frequency of discussing, comfort levels and less perceived barriers due to an intervention for healthcare professionals were seen in these studies. On the base of the review, it can be argued that face-to-face education with practice exercises are more effective than online interventions. However, the effectiveness of education for healthcare providers cannot be proven based on the existing literature. More longitudinal research is needed to optimized a format for educational interventions.

Attention regarding sexual healthcare should not only be focused on knowledge and training of the healthcare professionals, but also on organization of sexual healthcare within medical practice. Sexual health concerns are typically not prioritized in busy follow-up clinics focusing on cancer status. Helpful organizational factors concerning providing sexual healthcare by healthcare professional to patients were explored in **Chapter 8.** Healthcare professionals suggested it would be easier initiating the conversation if they had the opportunity to discuss patients' problems in a multidisciplinary team meeting to get advice. They considered the possibility to refer patients to a sexologist within their hospital as important. A recent evaluation within a Canadian cancer center showed that the introduction of specialized sexual health services within the hospital increased the frequency of healthcare professionals initiating a conversation about sexuality with their patients(43). The guideline 'interventions to address sexual problems in people with cancer' of the American Society of Clinical Oncology (ASCO) recommends clinicians to conduct an overview of experts and resources to address sexual health within their practice in order to deliver optimal sexual care to patients(38).

To treat specific sexuality issues caused by cancer, expertise in the complexity of cancer treatment and psychological support is fundamental. A trend is the formation of specialized cancer-related sexual health clinics(43, 45-47). Advantages include the availability of specialized knowledge, protected time to prioritize sexual health concerns within cancer care and provision of integrated biopsychosocial care. Studies which investigated specialized multidisciplinary sexuality programs within their hospitals faced different challenges, like lack of sustainable funding, lack of staff and excessive wait times due to heave usage of the clinic(42, 43, 45, 46). However, a specialized sexuality clinic would tackle some frequently reported barriers like lack of time and lack of knowledge. More research is needed on the implementation of sexual healthcare in oncology practice to deliver continuum of care, which will ultimately improve patient care.

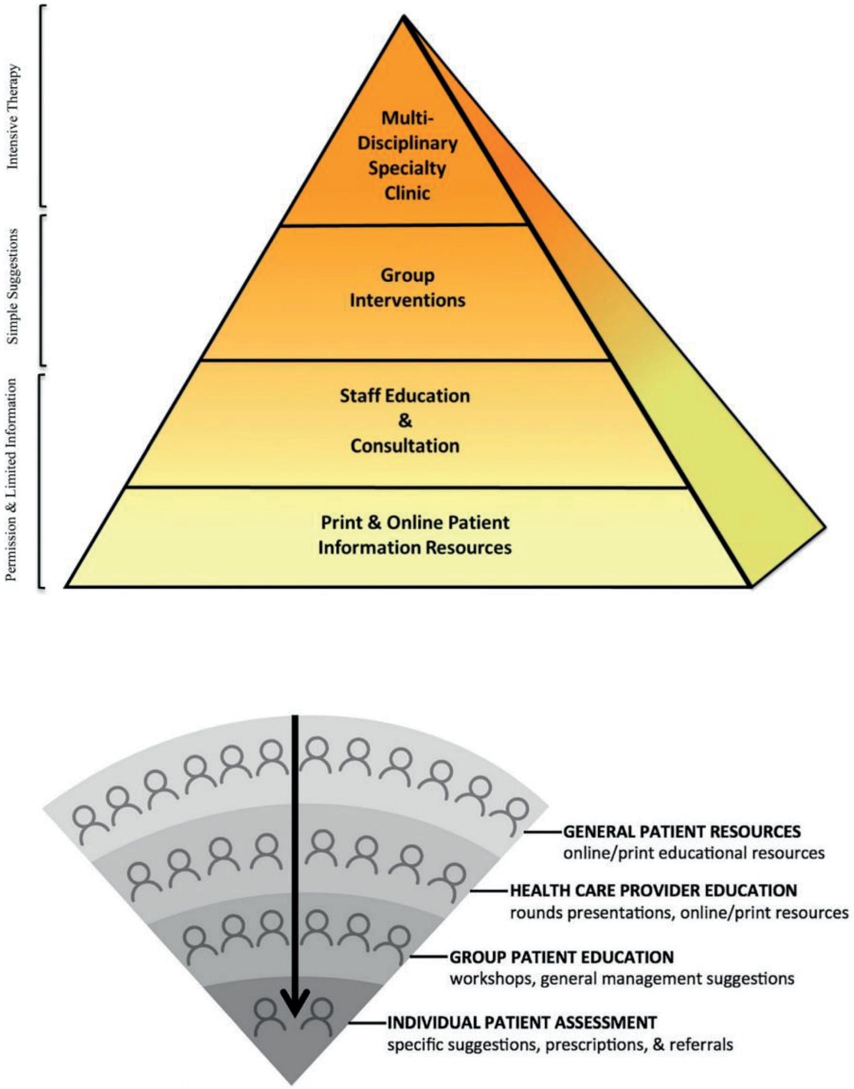


Figure 1: OASIS program model of sexual health care provision
Source: Duimering et al. *Support Care Cancer* (2019) and Walker et al. *J Canc Educ (2019)*.

REFERENCES

1. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. Journal of cancer survivorship : research and practice. 2016;10(3):600-9.
2. Raggio GA, Butryn ML, Arigo D, Mikorski R, Palmer SC. Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. Psychol Health. 2014;29(6):632-50.
3. Bober SL, Varela VS. Sexuality in adult cancer survivors: challenges and intervention. J Clin Oncol. 2012;30(30):3712-9.
4. Hoyer M, Johansson B, Nordin K, Bergkvist L, Ahlgren J, Lidin-Lindqvist A, et al. Health-related quality of life among women with breast cancer - a population-based study. Acta oncologica (Stockholm, Sweden). 2011;50(7):1015-26.
5. Boswell EN, Dizon DS. Breast cancer and sexual function. Translational andrology and urology. 2015;4(2):160-8.
6. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
7. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. Eur J Cancer Care (Engl). 2016;25(2):280-93.
8. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. Med J Aust. 2007;186(5):224-7.
9. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.
10. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. Soc Sci Med. 2007;64(8):1704-18.
11. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.
12. Jonker-Pool G, Hoekstra HJ, van Imhoff GW, Sonneveld DJ, Sleijfer DT, van Driel MF, et al. Male sexuality after cancer treatment--needs for information and support: testicular cancer compared to malignant lymphoma. Patient education and counseling. 2004;52(2):143-50.
13. Almont T, Couteau C, Etienne H, Bondil P, Guimbaud R, Schover L, et al. Sexual health and needs for sexology care in digestive cancer patients undergoing chemotherapy: a 4-month cross-sectional study in a French University Hospital. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018.
14. Hautamaki-Lamminen K, Lipiainen L, Beaver K, Lehto J, Kellokumpu-Lehtinen PL. Identifying cancer patients with greater need for information about sexual issues. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2013;17(1):9-15.
15. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World J Urol. 2006;24(4):423-8.
16. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Patient Discussion About Sexual Health With Health Care Providers After Cancer-A National Survey. The journal of sexual medicine. 2016;13(11):1686-94.
17. Lindau ST, Gavrilova N. Sex, health, and years of sexually active life gained due to good health: evidence from two US population based cross sectional surveys of ageing. BMJ (Clinical research ed). 2010;340:c810.
18. Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. Cancer Nurs. 2002;25(1):42-9.

19. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
20. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
21. Wootten AC, Meyer D, Abbott JM, Chisholm K, Austin DW, Klein B, et al. An online psychological intervention can improve the sexual satisfaction of men following treatment for localized prostate cancer: outcomes of a Randomised Controlled Trial evaluating My Road Ahead. Psycho-oncology. 2017;26(7):975-81.
22. Tuinman MA, Fleer J, Sleijfer DT, Hoekstra HJ, Hoekstra-Weebers JE. Marital and sexual satisfaction in testicular cancer survivors and their spouses. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2005;13(7):540-8.
23. Garos S, Kluck A, Aronoff D. Prostate cancer patients and their partners: differences in satisfaction indices and psychological variables. The journal of sexual medicine. 2007;4(5):1394-403.
24. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer Nurs. 2009;32(4):271-80.
25. Lehto US, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. European journal of cancer care. 2018;27(1).
26. Oldertroen Solli K, de Boer M, Nyheim Solbraekke K, Thoresen L. Male partners' experiences of caregiving for women with cervical cancer-a qualitative study. Journal of clinical nursing. 2019;28(5-6):987-96.
27. Miaja M, Platas A, Martinez-Cannon BA. Psychological Impact of Alterations in Sexuality, Fertility, and Body Image in Young Breast Cancer Patients and Their Partners. Rev Invest Clin. 2017;69(4):204-9.
28. Mehta A, Pollack CE, Gillespie TW, Duby A, Carter C, Thelen-Perry S, et al. What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study. Sexual medicine. 2019;7(2):184-91.
29. Geue K, Schmidt R, Sender A, Sauter S, Friedrich M. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. Psycho-oncology. 2015;24(11):1368-76.
30. Robinson L, Miedema B, Easley J. Young adult cancer survivors and the challenges of intimacy. Journal of psychosocial oncology. 2014;32(4):447-62.
31. Park BW, Hwang SY. Unmet Needs and Their Relationship with Quality of Life among Women with Recurrent Breast Cancer. Journal of breast cancer. 2012;15(4):454-61.
32. Krouwel EM, Albers LF, Nicolai MPJ, Putter H, Osanto S, Pelger RCM, et al. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
33. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC Suppl. 2014;12(1):41-53.
34. Kennedy V, Abramsohn E, Makelarski J, Barber R, Wroblewski K, Tenney M, et al. Can you ask? We just did! Assessing sexual function and concerns in patients presenting for initial gynecologic oncology consultation. Gynecol Oncol. 2015;137(1):119-24.
35. Martinez AM SJ, Ressle IB, Ayensu-Coker L, Thomas MA, Lindheim SR. Sexual satisfaction is reduced in the female patient and sexually intimate partners following cancer therapy Advances in Sexual Medicine. 2014;4:65-70.

36. Incrocci L, Jensen PT. Pelvic radiotherapy and sexual function in men and women. J Sex Med. 2013;10 Suppl 1:53-64.

37. Hendriks AC, Vries dMC. Recht op seksuele gezondheid en de rol van de arts. Nederlands Tijdschrift voor Geneeskunde. 2018;2018(162).

38. Carter J, Lacchetti C, Andersen BL, Barton DL, Bolte S, Damast S, et al. Interventions to Address Sexual Problems in People With Cancer: American Society of Clinical Oncology Clinical Practice Guideline Adaptation of Cancer Care Ontario Guideline. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2018;36(5):492-511.

39. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9.

40. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? J Sex Med. 2015;12(9):1927-39.

41. Sears CS, Robinson JW, Walker LM. A comprehensive review of sexual health concerns after cancer treatment and the biopsychosocial treatment options available to female patients. European journal of cancer care. 2018;27(2):e12738.

42. Duimering A, Walker LM, Turner J, Andrews-Lepine E, Driga A, Ayume A, et al. Quality improvement in sexual health care for oncology patients: a Canadian multidisciplinary clinic experience. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2019.

43. Walker LM, Wiebe E, Turner J, Driga A, Andrews-Lepine E, Ayume A, et al. The Oncology and Sexuality, Intimacy, and Survivorship Program Model: An Integrated, Multi-disciplinary Model of Sexual Health Care within Oncology. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.

44. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.

45. Matthew A L-CN, Jamnicky L, et al. The Prostate Cancer Rehabilitation Clinic: a biopsychosocial clinic for sexual dysfunction after radical prostatectomy. . Curr Oncol. 2018;25(6):393–402.

46. Barbera L, Fitch M, Adams L, Doyle C, Dasgupta T, Blake J. Improving care for women after gynecological cancer: the development of a sexuality clinic. Menopause (New York, NY). 2011;18(12):1327-33.

47. Carter J, Stabile C, Seidel B, Baser RE, Gunn AR, Chi S, et al. Baseline characteristics and concerns of female cancer patients/survivors seeking treatment at a Female Sexual Medicine Program. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2015;23(8):2255-65.

PART VI

APPENDICES

Nederlandse samenvatting

Kanker en seksuele gezondheid

Verbetering van diagnostiek en behandeling van kanker heeft geleid tot een stijging van overleving van patiënten met kanker. Circa zestig procent van de patiënten is 10 jaar na behandeling nog in leven. Steeds meer mensen leven dus met en na kanker. Hierdoor is in toenemende mate aandacht voor de bijwerkingen en langetermijneffecten door de behandeling van kanker, welke een negatief effect op de kwaliteit van leven van patiënten kunnen hebben. Een van deze langetermijneffecten zijn problemen met seksueel functioneren. Deze problemen kunnen ontstaan op moment van de diagnose en behandeling. Klachten blijven vaak aanwezig gedurende de follow-up. De klachten kunnen worden ervaren als een voortdurende herinnering aan de kanker, zelfs lange tijd na genezing. Problemen met seksueel functioneren kunnen voorkomen ongeacht leeftijd, geslacht, kankersoort of behandeling. Problemen kunnen alle domeinen van seksuele gezondheid bestrijken, zowel fysiek als psychisch.

De meeste problemen met seksueel functioneren worden niet veroorzaakt door de kanker zelf, maar door bijwerkingen van de behandeling. Verschillende soorten behandelen, zoals chirurgie, chemotherapie of bestraling, hebben specifieke bijwerkingen. De meest voorkomende bijwerking bij mannen zijn erectiele dysfunctie en vermindering van het libido. Bij vrouwen komt pijn tijdens gemeenschap en verminderde lubricatie het meeste voor. Verandering van zelfbeeld door bijvoorbeeld chirurgische behandelingen komt bij zowel mannen als vrouwen voor. Algemene bijwerkingen van behandeling zoals vermoeidheid, misselijkheid en incontinentie, kunnen ook oorzaken zijn van veranderingen in seksualiteit.

Ook partners van patiënten met kanker rapporteren een negatief effect van kanker op hun seksualiteit. Lichamelijke veranderingen, bijwerkingen van de behandeling en zien van hun partners als niet-seksueel door de ziekte dragen bij aan een verandering van de relatie.

Communicatie

De bijwerkingen en gevolgen van kanker en de behandeling op seksualiteit worden niet altijd door een hulpverlener besproken met de patiënt. Seksualiteit kan een moeilijk onderwerp zijn om te bespreken. Zo kunnen patiënten schaamte en gebrek aan privacy ervaren. Zorgverleners ondervinden barrières als gebrek aan tijd, gebrek aan kennis of aanwezigheid van derden. Uit eerder onderzoek blijkt de noodzaak om de voorlichting over en de begeleiding van de impact van kanker op seksuele gezondheid te verbeteren.

In **hoofdstuk 2** wordt een onderzoek beschreven die is uitgevoerd in samenwerking met de Nederlandse Federatie van Kankerpatiëntorganisaties (NFK) onder (ex)kankerpatiënten. Het doel van de studie was om te inventariseren hoe zorg en informatie omtrent seksuele gezondheid verbeterd kan worden. In totaal namen 2657 patiënten deel aan de studie. De meerderheid (65%) gaf aan behoefte te hebben aan informatie over seksualiteit en kanker. Patiënten jonger dan 61 jaar, patiënten die korter dan 2 jaar geleden gediagnostiseerd waren en patiënten die zelf een negatieve impact van kanker op seksualiteit rapporteerden, hadden significant meer behoefte aan informatie over de gevolgen van kanker op hun seksuele gezondheid. Ongeacht van het type kanker wilden patiënten het liefst praktische tips en praktische informatie over kanker en seksualiteit. Om communicatie over seksualiteit te verbeteren suggereerden respondenten dat zorgverleners de informatie standaard zouden kunnen aanbieden aan patiënten. Naar aanleiding van deze studie werd een website ontwikkeld (www.kankerenseks.nl) waar patiënten laagdrempelig informatie per ziektebeeld kunnen vinden.

In **hoofdstuk 3** wordt voor patiënten met prostaatkanker onderzocht wat belangrijke factoren zijn bij het voorspellen van tevredenheid over hun seksualiteit na radicale prostatectomie. Erectiele dysfunctie is de meest voorkomende bijwerking na een radicale prostatectomie. Erectiele dysfunctie herstel lang niet altijd en kan kwaliteit van leven verminderen – op korte en langer termijn. Patiënten, die voorafgaand aan de operatie geen erectiele dysfunctie hadden en postoperatief wel, werden voor deze studie maximaal tot drie jaar na de operatie gevolgd. De controle groep bestond uit patiënten die voorafgaand en na de operatie geen erectiele dysfunctie hadden. Het doel van de studie was te onderzoeken of seksuele tevredenheid verbetert gedurende follow-up en welke factoren geassocieerd zijn met tevredenheid. Patiënten die tussen 2006 en 2019 geopereerd werden, werden uitgenodigd om gevalideerde kwaliteit-van-leven vragenlijsten in te vullen; preoperatief 6, 12, 24 en 36 maanden postoperatief. De 'international index of erectile function' (IIEF) werd gebruikt voor het meten van erectiele functie en tevredenheid. Er werden 884 patiënten geïncludeerd voor analyse. Zij hadden een gemiddelde leeftijd van 62 jaar en een tevredenheid score van 8.4 (range: 2-10). De scores op 6, 12, 24 en 36 maanden follow-up daalden significant en waren 4.8, 4.8, 4.9 en 4.6 respectievelijk. In een univariate analyse bleken een hogere preoperatieve tevredenheidsscore, een hogere kwaliteit-van-leven score, een hogere erectiele functie score, lagere incontinentie score en hogere seksuele behoefte geassocieerd met meer tevredenheid op 24 en 36 maanden follow up. In een multiregressie analyse waren een hogere tevredenheidsscore preoperatief en een hogere seksuele behoefte geassocieerd met tevreden zijn; los van de ernst van erectiele dysfunctie. Zowel de bevinding dat de tevredenheidsscore niet toeneemt gedurende follow up als dat de tevredenheidsscore preoperatief voorspellend is voor de tevredenheid suggereert dat erectiele functie zelf niet de belangrijkste component is voor seksuele tevredenheid. In de praktijk vraagt de uroloog met name naar erectiele dysfunctie in de follow-up na radicale prostatectomie. Een andere aanpak van de voorlichting en psychoseksuele support voor patiënten met erectiele dysfunctie na radicale prostatectomie lijkt belangrijk.

In **hoofdstuk 4** wordt onderzoek beschreven waarin partners van patiënten met kanker deel namen, opnieuw in samenwerking met de NFK. Het is bekend dat partners een negatief effect van kanker op seksualiteit kunnen ervaren die impact kan hebben op de relatie. Het doel van dit landelijke onderzoek was om te identificeren welke factoren geassocieerd waren met de impact van kanker op partners' seksualiteit, welke partners meer behoefte hebben aan informatie en hoe dit ingebed kan worden in de huidige zorg. In totaal namen 230 partners deel aan het onderzoek. Significant meer vrouwen (65%) dan mannen (45%) rapporteerden een negatieve impact van kanker op de seksualiteit. Ook partners van patiënten die externe radiotherapie of hormoontherapie hadden ondergaan rapporteerden significant vaker een negatieve impact. Leeftijd en stadium van de ziekte waren niet geassocieerd met een grotere impact. Zestig procent van alle onderzochte partners had behoefte aan informatie over de gevolgen van kanker op seksualiteit. Partners die zelf een negatieve impact van kanker op seksualiteit rapporteerden, hadden een significant vaker behoefte aan informatie. Leeftijd, geslacht, stadium van de ziekte, tijd sinds diagnose en type behandeling waren niet gerelateerd aan meer behoefte aan informatie. Zoals ook uit de data beschreven in **hoofdstuk 2** blijkt**,** geven partners de voorkeur aan zorgverleners die informatie actief aanbieden. Partners willen zowel praktische tips en informatie als ervaringen van anderen. Als aanbeveling uit deze studie werd geformuleerd informatie voor partners te ontwikkelen en deze gemakkelijk toegankelijk te maken.

In **hoofdstuk 5** wordt door middel van een multicenter studie onderzoek gedaan naar borstkankerpatiënten en hun partners. De incidentie van seksuele dysfunctie na behandeling voor borstkanker is hoog. De meerderheid van de patiënten (80%) en hun partners (74%) ontving geen informatie over mogelijke bijwerkingen van de behandeling op seksueel functioneren. Hoewel slechts een kwart van de respondenten een directe behoefte aan informatie rapporteerden, zouden de meeste de mogelijkheid om de gevolgen van behandeling op seksualiteit te bespreken op prijs stellen. De verpleegkundig specialist werd door zowel patiënt als partner als de meest geschikte hulpverlener aangewezen om dit onderwerp mee te bespreken; aangevuld met een brochure of informatie via een website. Patiënten ontvangen informatie het liefst ten tijden van de behandeling, partners prefereerden informatie al voorafgaand aan een behandeling. Seksueel functioneren wordt beschouwd als een belangrijk aspect voor de kwaliteit van leven van patiënten met borstkanker en is tevens geïncludeerd in de “value-based patient-centred outcomes” die worden gebruikt voor het meten van patiëntgebonden uitkomsten voor vrouwen met borstkanker. Goede voorlichting is hierbij belangrijk.

In **hoofdstuk 6** wordt inzicht verkregen over de handelswijze van medisch oncologen ten aanzien van het bespreekbaar maken van door behandeling veroorzaakte seksuele bijwerkingen. De meerderheid (82%) van de 120 deelnemende oncologen besprak seksueel functioneren met minder dan de helft van de patiënten. Driekwart van de oncologen achtte het tot hun verantwoordelijkheid om het onderwerp bespreekbaar te maken. De oncologen die invloed van kanker en behandeling op seksueel functioneren wel bespraken, deden dat vaker met jonge patiënten en patiënten met een in opzet curatieve behandeling. Belangrijke barrières voor de oncologen waren gebrek aan tijd en training en de hoge leeftijd van de patiënt. Driekwart van de oncologen zou meer training willen om seksueel functioneren te bespreken met patiënten. Seksuele dysfunctie kan worden gezien als een bijwerking van behandeling en zou besproken kunnen worden tijdens het informed consent gesprek, zoals bijvoorbeeld de American Society of Clinical Oncology adviseert. Het lijkt ook belangrijk om binnen het behandelteam de verantwoordelijkheid om dit onderwerp te bespreken af te spreken.

Jongvolwassenen met kanker (adoloscents and young adults with cancer; AYAs, leeftijd 15-39 jaar) vormen een speciale groep binnen de oncologie. Anders dan volwassenen, worden zij getroffen door kanker in een levensfase waar psychosociale ontwikkeling op de voorgrond staat. Hieronder valt ook de (psycho)seksuele ontwikkeling. AYAs kunnen dezelfde maar ook andere klachten dan volwassenen krijgen. Deze blijven vaker dan bij volwassenen bestaan op lange termijn. Dit kan schadelijk zijn voor de psychosociale ontwikkeling van de AYA. De zorg en informatie zou daar beter op aangepast kunnen worden, blijkt uit **hoofdstuk 7.** In totaal namen 61 AYAs en 54 zorgverleners tegelijktijdig deel aan een crossectionele survey. Communicatie over de impact van kanker en behandeling op seksualiteit werd belangrijk geacht door meer dan 90% van de AYAs en zorgverleners. Van de AYAs ontving 40% informatie over seksualiteit en slechts 21% was daar tevreden mee. AYAs bespreken seksualiteit liever met een verpleegkundige specialist of seksuoloog dan met hun oncoloog. Belangrijke barrières om het onderwerp niet te bespreken, waren een gevoel van schaamte bij de AYA, en aanwezigheid van derden voor de zorgverlener. De meeste AYAs zouden het liefst gepersonaliseerde informatie via een website of een gesprek met de zorgverlener voorafgaand aan de behandeling krijgen. Het tijdig krijgen van goede informatie is belangrijk voor realistische verwachtingen rondom seksuele functioneren en coping met de ziekte. De discrepantie tussen AYA en zorgverlener laten zien dat betrokkenheid van de AYA in de vormgeving van zorg belangrijk is.

In **hoofdstuk 8** werd middels kwalitatief onderzoek meer inzicht verkregen in de een ideale vorm van informatie verstrekking over seksualiteit binnen de gespecialiseerde AYA zorg. Zes oncologen/hematologen en acht verpleegkundig specialisten werkzaam in een van de Nederlandse ziekenhuizen gespecialiseerd in AYA zorg namen deel aan semigestructureerd interviews. In de interviews kwamen de volgende thema's naar voren (1) verantwoordelijkheid om seksuele gezondheid te bespreken, (2) optimale timing, (3) faciliterende factoren, (4) hulpmiddelen, (5) voorlichtingsmateriaal.
De ideale manier om seksualiteit bespreekbaar te maken verschilt per zorgverlener. Het verdelen van de verantwoordelijkheid binnen het team om seksualiteit te bespreken is belangrijk om te waarborgen dat voorlichting daadwerkelijk plaatsvindt. Een optimale timing voor het bespreken van seksueel functioneren is er niet, aldus de zorgverleners. Juist herhaaldelijk bespreekbaar maken van het onderwerp wordt belangrijk geacht. Om seksueel functioneren makkelijker bespreekbaar te maken noemden de geïnterviewden naast verschillende communicatie tips, ook onderwijs voor zorgverleners en een multidisciplinaire aanpak van problemen middels een MDO en verwijsmogelijkheden naar een seksuoloog. Als tools kunnen een screenende vragenlijst voor de AYA voorafgaand aan het consult, een checklist in het elektronisch patiëntendossier en voorlichtingsmateriaal hen helpen om seksualiteit makkelijker te bespreken. Voorlichtingsmateriaal zou in ieder geval online beschikbaar moeten zijn en ziekte specifieke informatie over bijwerkingen en 'do's and don'ts' kunnen bevatten. Tenslotte is de input van AYAs voor hun eigen zorgbehoefte essentieel voor de uiteindelijke vormgeving.

In de literatuur en in deze thesis blijkt dat gesprek aan onderwijs en training van de zorgverlener een factor is die bijdraagt aan gebrek aan communicatie over seksualiteit. In **hoofdstuk 9** werd middels een systematische review uitgezocht welke vormen van onderwijs of training bestaan voor zorgverleners werkzaam binnen de oncologie, en of deze effectief zijn. Zeven studies werden geïncludeerd waar in totaal 572 zorgverleners deelnamen aan een interventie. Bij één van deze zeven studies was de interventie geheel online. De studies lieten onder andere een verbetering zien in kennis en frequentie van bespreken na de interventie. Ook rapporteerden de zorgverleners zich minder gehinderd door barrières bij het bespreken van seksualiteit. Er kon geen conclusie getrokken worden over de daadwerkelijke effectiviteit van de interventies en over welke soort interventie. Dit kwam door de beperkte kwaliteit van de studies, onder andere door grote heterogeniteit tussen de studies, korte follow-up en het ontbreken van een controle groep in de studies.

Ook andere factoren, die niet in dit proefschrift werden onderzocht, zouden kunnen bijdragen aan het verbeteren van de communicatie over de gevolgen van kanker op seksualiteit. In het **hoofdstuk 10** worden mogelijke factoren en richtingen voor onderzoek beschreven. Een polikliniek met beperkte ingeplande tijd per patiënt lijkt niet de beste omgeving om seksualiteit te bespreken. Een recente studie uit een Canadees kankercentrum liet zien dat door de introductie van een gespecialiseerde ‘sexual health services’ zorgverleners vaker seksualiteit aankaartten, omdat ze een mogelijkheid hadden hiernaar door te verwijzen bij problemen. De ASCO raadt daarom zorgverleners aan om een overzicht beschikbaar te hebben van bronnen en verwijsmogelijkheden binnen eigen ziekenhuis. Gespecialiseerde medische en psychosociale zorg voor problemen met seksualiteit kunnen worden geleverd in dergelijke gespecialiseerde klinieken worden. Bekostiging, te kort aan personeel en lange wachttijden voor de patiënten blijken uitdagingen voor deze vorm van aanbieden seksuele gezondheidszorg. Meer onderzoek naar het implementatie van seksuele gezondheidszorg, voor kankerpatiënten die impact van behandeling op seksueel functioneren ervaringen met een hulpvraag, is nodig om patiëntenzorg op dit gebied uiteindelijk te verbeteren.

Appendix 2.
Questionnaire chapter 2

Questionnaire (translated from Dutch)

Part 1: demographics

- ☐ Male
- ☐ Female

1. What is your age? _____________years

2. Which type of cancer did / do you have?
   - ☐ Breast
   - ☐ Prostate
   - ☐ Gastro-intestinal
   - ☐ Gynaecology
   - ☐ Bladder and kidney
   - ☐ Head neck
   - ☐ Skin
   - ☐ Male external genitalia
   - ☐ Endocrinology
   - ☐ Haematology
   - ☐ Lung
   - ☐ Bone
   - ☐ Other: ______________________________________

3. Which stage of cancer do you have/had?
   - ☐ Local disease
   - ☐ Metastatic disease
   - ☐ I don’t know

4. How long ago were you diagnosed with cancer?
   - ☐ Less than 2 ago
   - ☐ 3 – 5 years ago
   - ☐ 6 – 10 years ago
   - ☐ More than 10 years ago
   - ☐ I don’t know

5. Which treatment did you received? *(multiple answers possible)*
   - ☐ None
   - ☐ Surgery
   - ☐ External radiotherapy
   - ☐ Internal radiotherapy
   - ☐ Hormonal therapy
   - ☐ Chemotherapy
   - ☐ Immunotherapy
   - ☐ Stem-cell therapy
   - ☐ Other: ______________________________________

6. Did you actively search for information about intimacy and sexuality? *(multiple answers possible)*

☐ No
☐ Yes

7. Where did you search for information about intimacy and sexuality? (open question; not required)

8. Are you satisfied with the information about intimacy and sexuality you found?

☐ Yes
☐ No

9. Why were(n't) you satisfied with the information? (open question; not required)

10. What kind of information regarding intimacy and sexuality do you prefer?

☐ I don't have a need for information now
☐ Practical tips
☐ Experiences from others
☐ Contact with other cancer patients
☐ Practical information (prevalence and cause of sexuality issues)
☐ A referral to a professional
☐ Information for partners
☐ Information for care providers
☐ Information video's
☐ Other:……………………………………………………………

11. Did your intimacy or sexuality change due to the diagnosis cancer?

☐ No, it did not change
☐ Yes, it became better
☐ Yes, it became worse

12. As a result of cancer, what kind of changes in sexuality or intimacy did you experience?

☐ Physical changes
☐ Psychological changes
☐ Changes self-image
☐ Other:____

13. Which physical sexuality problems did you experience? *(multiple answers possible)*

☐ I do not experience physical problems
☐ Pain during sexual intercourse
☐ Erection problems
☐ Dry mouth
☐ Lubrication problems
☐ Hormonal changes
☐ Fatigue
☐ Incontinence of urine or defecation
☐ Problems with ejaculation
☐ Unable to ejaculate
☐ Other:____

14. Which other intimacy or sexuality problems did you experience?

☐ I do not experience other problems
☐ I do not experience problems, but had to get used to the changes in sexuality
☐ No sexual arousal
☐ No sexual desire
☐ I am afraid to have sexual intercourse
☐ The character of my sexual relationship have changed a lot
☐ No sex drive
☐ My self-image has changed
☐ I feel deformed
☐ I think my partner experience difficulties with my changed body
☐ I think my partner do not have sexual desire
☐ I am afraid to approach my partner
☐ Other: ______________________________________

15. How do you deal with sexuality and intimacy problems?

☐ I do nothing (skip question 17)
☐ I do not experience problems
☐ I discuss the problems with my (sexual) partner
☐ I discuss the problems with friends
☐ I discuss the problems with other patients
☐ I discuss the problems with my healthcare provider
☐ I seek for professional help by a sexologist/psychologist
☐ I used medication
☐ I used an aid
☐ I searched for information via internet
☐ I searched for information via a patient organization
☐ Other: ______________________________________

16. What did help you to improve intimacy and sexuality, and why? (open question, not required)

17. Why did you choose to do nothing?

☐ I accepted the situation and I am fine with it
☐ I accepted the situation, but I am not fine with it
☐ I am afraid to hurt my partner, so I do not talk about the sexuality problems
☐ I do not dare to discuss my problems with anyone
☐ I do not think there is a solution
☐ I do not know where I can go for help
☐ I do not feel comfortable to discuss my problems with my health
☐ care provider
☐ The treatment I want is not covered by my health care insurance
☐ Survival is more important at this moment
☐ I thought, it was part of it
☐ Other: ______________________________________

18. Could you explain why nothing helped you? (open question, not required)

19. You find some statements below. Choice one of the following answers by each statement.
    - Totally disagree
    - Disagree
    - Agree
    - Totally agree
    - Not applicable
    - I don’t know

    a. I am satisfied with my sex life
    b. It is easy for me to discuss my thoughts and feelings about sex with my (sexual) partner
    c. I do not have sexual desire anymore due to the cancer
    d. Intimacy between me and my partner was better before the cancer
    e. My sex life was better before the cancer
    f. I have learned to deal with changes in sexuality

20. What do you recommend to other cancer patients with regard to (discussing) intimacy and sexuality? (open question, not required)

21. What do you recommend to partners of cancer patients with regard to (discussing) intimacy and sexuality? (open question, not required)

22. What do you recommend to health care providers with regard to discussing intimacy and sexuality?
    ☐ My health care provider should initiate the discussing about sexuality
    ☐ My health care provider should provide information systematically
    ☐ My health care provider should involve my partner when discussing sexuality
    ☐ My health care provider should provide an referral to another specialist/sexologist in an approachable manner
    ☐ Other: ____

23. What do you want to know about sexuality (after cancer), but never dared to ask?

Questions about your relationship state

24. Do you have a relationship?
    ☐ No (skip question 26 and 27)
    ☐ Yes
    ☐ I do not want to answer this question

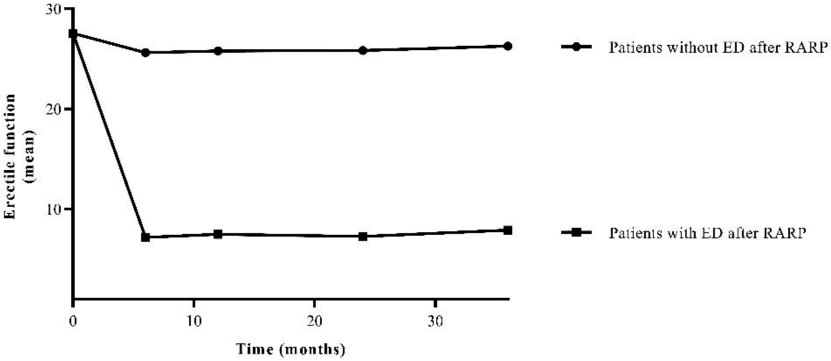
25. Did you have the relationship already **before** you were diagnosed with cancer?
    ☐ Yes
    ☐ No

26. Partner of patients with cancer might suffer from intimacy and sexuality problems as well. Therefore, we would like to send a similar questionnaire the partners as well. May we approach your partner?
    ☐ No
    ☐ Yes

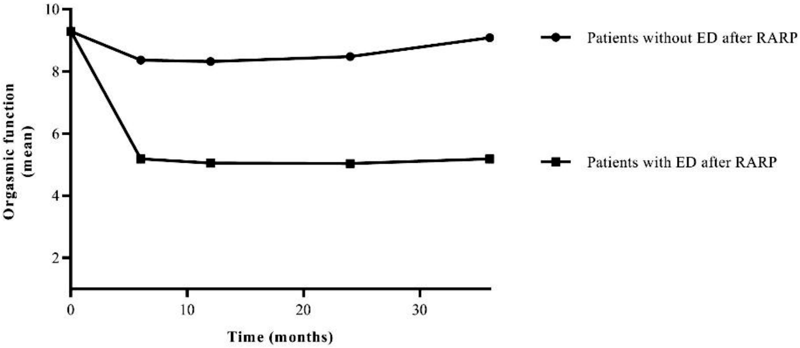
27. Do you have additional comments? (not required)

    ____

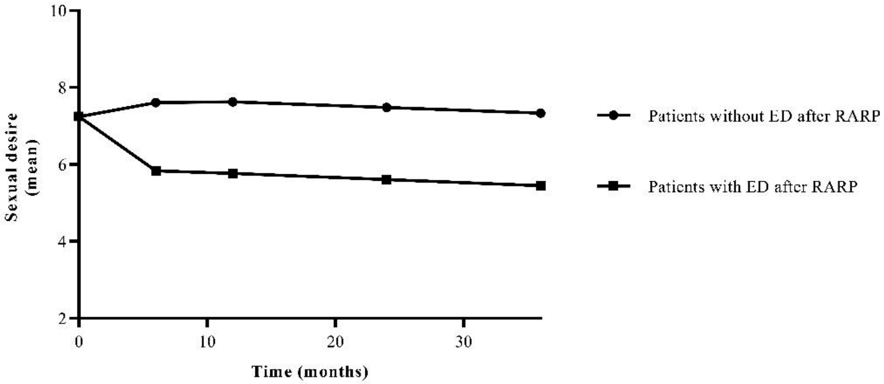
Appendix 3.
Supplementary information (SI) chapter 3



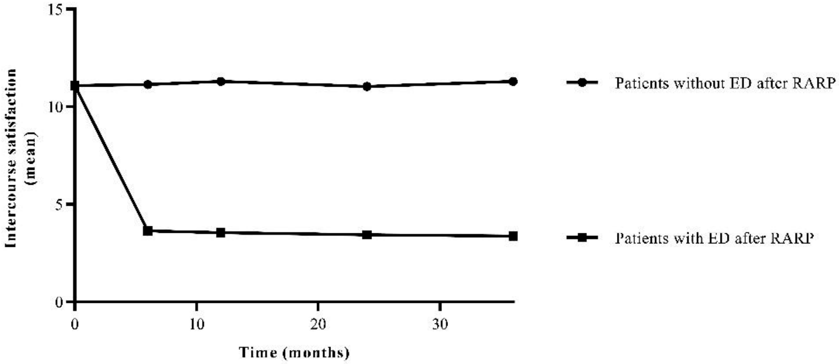
SI Figure 1: Erectile function score (range 1-30) (subdomain of IIEF-15)



SI Figure 2: Orgasmic function score (range 1-10) (subdomain of IIEF-15)



SI Figure 3: Sexual desire score (range 2-10) (subdomain of IIEF-15)



SI Figure 4: Intercourse satisfaction score (range 0-15) (subdomain of IIEF-15)

Appendix 4.
Questionnaire chapter 4

Questionnaire (translated from Dutch)

Part 1: demographics

1. What is your gender?
   - ☐ Male
   - ☐ Female

2. What is your age? _____________years

3. Which type of cancer did / do your partner have/had?
   - ☐ Breast
   - ☐ Prostate
   - ☐ Gastro-intestinal
   - ☐ Gynaecology
   - ☐ Bladder and kidney
   - ☐ Head neck
   - ☐ Skin
   - ☐ Male external genitalia
   - ☐ Endocrinology
   - ☐ Haematology
   - ☐ Lung
   - ☐ Bone
   - ☐ Other: ______________________________________

4. Which stage of cancer did / do your partner have/had?
   - ☐ Local disease
   - ☐ Metastatic disease
   - ☐ I don't know

5. How long ago was your partner diagnosed with cancer?
   - ☐ Less than 2 ago
   - ☐ 3 – 5 years ago
   - ☐ 6 – 10 years ago
   - ☐ More than 10 years ago
   - ☐ I don't know

6. Which treatment did your partner received? *(multiple answers possible)*
   - ☐ None
   - ☐ Surgery
   - ☐ External radiotherapy
   - ☐ Internal radiotherapy
   - ☐ Hormonal therapy
   - ☐ Chemotherapy
   - ☐ Immunotherapy
   - ☐ Stem-cell therapy
   - ☐ Other: ______________________________________

7. Did you actively search for information about intimacy and sexuality after cancer? *(multiple answers possible)*
   - ☐ No
   - ☐ Yes

8. Are you satisfied with the information about intimacy and sexuality you found?
   - ☐ Yes
   - ☐ No

9. Where did you search for information about intimacy and sexuality? (open question; not required)

10. Why were(n't) you satisfied with the information? (open question; not required)

11. What kind of information regarding intimacy and sexuality do you prefer?
    - ☐ I don't have a need for information now
    - ☐ Practical tips
    - ☐ Experiences from others
    - ☐ Contact with other cancer patients
    - ☐ Practical information (prevalence and cause of sexuality issues)
    - ☐ A referral to a professional
    - ☐ Information for partners
    - ☐ Information for care providers
    - ☐ Information videos
    - ☐ Other:………………………………………………

12. Did your intimacy or sexuality in your relationship change due to the cancer of your partner?
    - ☐ No, it did not change
    - ☐ Yes, it became better
    - ☐ Yes, it became worse

13. As a result of cancer, what kind of changes in sexuality or intimacy did you experience?
    - ☐ Physical changes
    - ☐ Psychological changes
    - ☐ Both physical and psychological changes
    - ☐ Changes in self-image
    - ☐ Other:____

14. Which physical sexuality problems did you experience? *(multiple answers possible)*
    - ☐ We did not experience physical problems
    - ☐ My partner experiences pain during sexual intercourse
    - ☐ My partner experiences erection problems
    - ☐ My partner experiences a dry mouth
    - ☐ My partner experiences lubrication problems
    - ☐ My partner experiences hormonal changes
    - ☐ My partner is too fatigue to have sexual intercourse
    - ☐ I am too fatigue to have sexual intercourse
    - ☐ My partner has incontinence of urine or defecation
    - ☐ My partners experiences problems with ejaculation
    - ☐ My partner is unable to ejaculate
    - ☐ Other:____

15. Which other intimacy or sexuality problems did you experience?
    - ☐ I do not experience other problems
    - ☐ I do not experience problems, but have to get used the changes in sexuality
    - ☐ My partner do not have sexual arousal
    - ☐ I have no sexual desire
    - ☐ My partner has no sexual desire
    - ☐ I think my partner is too afraid to have sexual intercourse
    - ☐ The character of our sexual relationship has changed a lot
    - ☐ I have no sex drive
    - ☐ The self-image of my partner has changed
    - ☐ My partner thinks he/she is deformed
    - ☐ I experience difficulties with the changed body of my partner
    - ☐ I think my partner do not have sexual desire
    - ☐ I am afraid to force my partner
    - ☐ Other: ______________________________________

16. How do you deal with sexuality and intimacy problems?
    - ☐ I do nothing (skip question 17)
    - ☐ I do not experience problems
    - ☐ I discuss the problems with my (sexual) partner
    - ☐ I discuss the problems with friends
    - ☐ I discuss the problems with other patients
    - ☐ I discuss the problems with my health care provider
    - ☐ I seek for professional help by a sexologist/psychologist
    - ☐ I used medication
    - ☐ I used an aid
    - ☐ I searched for information via internet
    - ☐ I searched for information via a patient organization
    - ☐ Other: ______________________________________

17. What did help you to improve intimacy and sexuality, and why? (open question, not required)

18. Why did you choose to do nothing?
    - ☐ I accepted the situation and I am fine with it
    - ☐ I accepted the situation, but I am not fine with it
    - ☐ I am afraid to hurt my partner, so I do not talk about the sexuality problems
    - ☐ I do not dare to discuss my problems with anyone
    - ☐ I do not think there is a solution
    - ☐ I do not know where I can go for help
    - ☐ I do not feel comfortable to discuss my problems with my health care provider
    - ☐ The treatment I want is not covered by my health care insurance
    - ☐ Survival is more important at this moment
    - ☐ I thought, it was part of it
    - ☐ Other: ______________________________________

19. Tell in your own words why nothing did help you? (open question, not required)

20. You find some statements below. Choice one of the following answers by each statement.
    - Totally disagree
    - Disagree
    - Agree
    - Totally agree

- Not applicable
- I don't know
-

g. I am satisfied with my sex life
h. I am comfortable to discuss my thoughts and feelings about sex with my (sexual) partner
i. I do not have sexual desire due to the cancer of my partner
j. Intimacy between me and my partner was better before the cancer
k. My sex life was better before the cancer
l. I have learned to deal with my changed sexuality

21. What do you recommend to others people dealing with cancer with regard to discussing intimacy and sexuality? (open question, not required)

22. What do you recommend to partners of cancer patients with regard to discussing intimacy and sexuality? (open question, not required)

23. What do you recommend to health care provider with regard to discussing intimacy and sexuality?
    - ☐ My health care provider should initiate the discussing about sexuality
    - ☐ My health care provider should provide information systematically
    - ☐ My health care provider should involve my partner when discussing sexuality
    - ☐ My health care provider should provide an referral to another specialist/sexologist in an approachable manner
    - ☐ Other: ______________________________________

24. What do you want to know about sexuality (after cancer), but never dared to ask?

Appendix 5.
Questionnaire chapter 5, part 1

Questionnaire patient (translated from Dutch)

Choose the most suitable answer. Thank you in advance for your effort.

Part 1: demographics

1. What is your age? _____________years

2. What is your ethnicy?
   - ☐ Dutch
   - ☐ Other:____

3. What is your marital status?
   - ☐ Single
   - ☐ In a relationship, living together
   - ☐ In a relationship, not living together
   - ☐ Married
   - ☐ Widowed
   - ☐ Other:____

4. If you are in a relationship, for how long?
   - ☐ ….years

5. Level of education?
   - ☐ Elementary school
   - ☐ Middle school
   - ☐ High school
   - ☐ College
   - ☐ University
   - ☐ Other:…………………………………….

6. Are you currently employed?
   - ☐ Yes
   - ☐ No, I am in between jobs
   - ☐ No, not able to work due to my illness
   - ☐ No, I am retired
   - ☐ Other:____

Part 2: Diagnosis and treatment

7. Which stage of breast cancer do you have/had?
   - ☐ A premalign stage (ductal carcinoma in situ)
   - ☐ Breastcancer only in the breast itself
   - ☐ With metastasis in the axilla(s)
   - ☐ With metastasis elsewhere in the body

8. How long ago were you diagnosed with breast cancer?

☐ 0 – 3 months ago
☐ 3 – 6 months ago
☐ 6 months – 1 year ago
☐ 1 – 2 years ago
☐ more than 2 ago

9. Which surgical treatments did you underwent? *(multiple answers possible)*

☐ No operation
☐ Breast conserving surgery
☐ Mastectomie, without construction of the breast
☐ Mastectomie, with direct construction of the breast
☐ Mastectomie, with secundary reconstruction of the breast
☐ Mastectomie of both breasts, without construction
☐ Mastectomie of both breasts, without direct construction
☐ Mastectomie of both breasts, without secundary construction
☐ Axillary lymph node dissection, one side
☐ Axillary lymph node dissection, both sides

10. Did you receive, besides surgery, other treatments? *(multiple answers possible)*

☐ No
☐ Radiotherapy after the operation
☐ Radiotherapy during the operation
☐ Chemotherapy before surgery
☐ Chemotherapy after surgery
☐ Endocrine therapy
☐ Immunotherapy (Herceptin)

11. To what extent were you concerned about your health when you heard the diagnosis breast cancer?

☐ No concerns
☐ Some concerns
☐ Many concerns
☐ Grave concerns

12. Have your concerns changes **after** treatment?

☐ Yes, my concerns are increased
☐ Yes, my concerns are declined
☐ No, my concerns didn’t change
☐ No, I had no concerns

13. If you are breast cancer-free, are you afraid that the breast cancer may come back?

☐ Inapplicable
☐ Not afraid
☐ A bit afraid
☐ Afraid
☐ Very afraid

Part 3: Your experience about intimacy and sexuality after disease

14. Were you sexually active **before** the diagnosis breast cancer?

☐ Yes
☐ No

15. Did you experience complaints in intimacy or sexuality before the diagnosis breastcancer?

☐ Yes, **go to question 16**
☐ No, **go to question 18**

16. Which intimacy or sexuality complaints did you have? *(multiple answers possible)*
    - ☐ Fatique
    - ☐ Feel uncertain about my appearance
    - ☐ Less intimacy with my partner
    - ☐ No enjoying sex anymore
    - ☐ No sex drive
    - ☐ Difficulties with orgasms
    - ☐ Pain during intercourse
    - ☐ Insufficient lubrication
    - ☐ Other:____

17. Did the intimacy or sexuality complaints changes **after** the diagnosis of breast cancer?
    - ☐ No, complaints didn't change
    - ☐ Yes, complaints have disappeared
    - ☐ Yes, complaints have declined
    - ☐ Yes, complaints have increased
    - ☐ Yes, complaints have changed

18. Are you **after** treatment sexually active?
    - ☐ Yes
    - ☐ No

19. Did you experience new complaints with regard to intimacy or sexuality due though the breast cancer or the treatment?
    - ☐ Yes, **go to question 20**
    - ☐ No, **go to question 25**

20. Which complaints did you experience? *(multiple answers possible)*
    - ☐ Fatique
    - ☐ Feel uncertain about my appearance
    - ☐ Feel uncertain about changes body image
    - ☐ Less intimacy with my partner
    - ☐ No enjoying sex anymore
    - ☐ No sex drive
    - ☐ Difficulties with orgasms
    - ☐ Pain during intercourse
    - ☐ Insufficient lubrication
    - ☐ Menopausal complaints
    - ☐ Other:____

21. On a scale of 0-10, in which amount did you suffer from these complaints?

    0 means no suffering, 10 means a lot of suffering

    Grade: …….

22. Did one of your therapists ever offered you help for these complaints?
    - ☐ Yes, by advising tools (for example lubricant)
    - ☐ Yes, by tips on other forms of intimacy
    - ☐ Yes, other: ______________________________
    - ☐ No, **go to question 25**

23. Were you satisfied with the help you were offered?
    - ☐ Yes
    - ☐ No

24. Are you referred, by your therapist, for your sexual of intimacy complaints?

☐ Yes, to:______________________________ (for example other specialist or sexologist)
☐ No, but I would have wanted a referral
☐ No, I had no need of a referral Nee, ik had daar geen behoefte aan

Part 4: Information about intimacy and sexuality

25. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?

☐ Yes
☐ No

26. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment?

☐ Yes, **go to question 27**
☐ No, **go to question 31**

27. At what stage did you receive the information about intimacy and sexuality? *(multiple answers possible)*

☐ At the same time as the diagnosis breast cancer
☐ Before chemotherapy before surgery
☐ Before the operation
☐ After the operation
☐ Before the additional treatment*
☐ During the additional treatment
☐ At the end of all treatments
☐ Other: ____

**With additional treatment is meant chemotherapy, radiotherapy and/or endocrine therapy*

28. Did you have to ask for information about intimacy or sexuality?

☐ Yes, I had to ask for this information by myself
☐ No, the care provider gave the information from
☐ No, it was clear to me where I could find information (for example a flyer or on the web)

29. Who gave you the information about intimacy and sexuality? *(multiple answers possible)*

☐ General practitioner
☐ Surgeon
☐ Nurse on the breast cancer outpatient clinic
☐ Oncologist
☐ Radiotherapist
☐ Plastic surgeon
☐ Psychologist
☐ Sexologist
☐ Social worker
☐ Someone else:_____________________________________

30. How did you receive information about intimacy and sexuality? *(multiple answers possible)*

☐ Patient flyer
☐ Via other (breast) cancer patients
☐ By an information moment for patients with breast cancer
☐ By Dutch Breast cancer Society (Borstkankervereniging Nederland)
☐ By Dutch Cancer Society (KWF Kankerbestrijding)
☐ By a web page about breast cancer and sexuality

☐ In a conversation with a healthcare professional
☐ Other:____

31. Did you actively searched for information about intimacy and sexuality? *(multiple answers possible)*
☐ No, I didn't searched for information
☐ Yes, on the internet
☐ Yes, via Dutch Breast cancer Society (Borstkankervereniging Nederland)
☐ Yes, Dutch Cancer Society (KWF Kankerbestrijding)
☐ Yes, Via other (breast) cancer patients
☐ Yes, via family or friends
☐ Other:____

32. Are you satisfied with the information about intimacy and sexuality?
☐ Yes, **go to question 34**
☐ No, **go to question 33**
☐ Inapplicable, **go to question 34**

33. What could have been better about the information? *(multiple answers possible)*
☐ The amount was insufficient
☐ The information was too general, it was not about my situation
☐ The content of the information was incorrect
☐ The moment of the information was too late
☐ The moment of informatie was too early
☐ I have asked for information, but I didn't receive any
☐ The healthcare professional should have given me the information
☐ I have no need for information
☐ Other:____

34. What is, according to you, the best way of receiving information about intimacy and sexuality? *(multiple answers possible)*
☐ Patient flyer
☐ Via an application on a tablet or phone (E-health)
☐ By a web page about breast cancer and sexuality
☐ By Dutch Breast cancer Society (Borstkankervereniging Nederland)
☐ By Dutch Cancer Society (KWF Kankerbestrijding)
☐ By a patient forum on the internet
☐ By a group meeting with other patients lead by a healthcare professionals
☐ In a conversation with other (breast) cancer patients
☐ In a conversation with a healthcare professional
☐ None, I have no need for information
☐ Other:____

35. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? *(multiple answers possible)*
☐ At the same time as the diagnosis breast cancer
☐ Before chemotherapy before surgery
☐ Before the operation
☐ After the operation
☐ Before the additional treatment*
☐ During the additional treatment
☐ At the end of all treatments
☐ Other: ____

**With additional treatment is meant chemotherapy, radiotherapy and/or endocrine therapy*

Part 5: Discussing intimacy and sexuality with a healthcare professional

36. Who should, according to you, initiate the discussing about intimacy and sexuality?
    - ☐ Me
    - ☐ My partner
    - ☐ General practitioner
    - ☐ Surgeon
    - ☐ Nurse on the breast cancer outpatient clinic
    - ☐ Oncologist
    - ☐ Radiotherapist
    - ☐ Plastic surgeon
    - ☐ I don’t want to discuss the subject
    - ☐ Other:____

37. With which health care professional would you prefer discussing intimacy and sexuality? *(multiple answers possible)*
    - ☐ General practitioner
    - ☐ Surgeon
    - ☐ Nurse on the breast cancer outpatient clinic
    - ☐ Oncologist
    - ☐ Radiotherapist
    - ☐ Plastic surgeon
    - ☐ Psychologist
    - ☐ Sexologist
    - ☐ Social worker
    - ☐ I don’t want to discuss the subject with a health care professional
    - ☐ Other:____

38. What was for you a reason **not** to start a conversation about intimacy and sexuality with a health care professional? *(multiple answers possible)*
    - ☐ Inapplicable, I did ask my questions about intimacy and sexuality
    - ☐ I have no need
    - ☐ A feeling of shame
    - ☐ Intimacy and sexuality are private
    - ☐ I am too sick for discussing intimacy and sexuality
    - ☐ There is nothing to do about it
    - ☐ Intimacy and sexuality are no priority
    - ☐ I would rather discuss this subject with my partner
    - ☐ I don’t have a partner
    - ☐ The health care professional is too busy
    - ☐ The health care provider didn’t initiate the discussion
    - ☐ The health care professional was not open for discussing this subject
    - ☐ The health care professionals is a man
    - ☐ The age of the health care professional
    - ☐ This subject doesn’t belong to a health care professional
    - ☐ Lack of privacy, I was with my partner
    - ☐ Lack of privacy, I was with friends/familiy
    - ☐ Lack of privacy, due to other health care professionals (for example an intern)
    - ☐ Other:____

39. Statement: Every breast cancer patient should offered a conversation about intimacy and sexuality, **before treatment**.
    - ☐ Agree

☐ Disagree
☐ I don’t know

40. Statement: : Every breast cancer patient should offered a conversation about intimacy and sexuality, **<u>during treatment</u>**.
    ☐ Agree
    ☐ Disagree
    ☐ I don’t know

41. Statement: : Every breast cancer patient should offered a conversation about intimacy and sexuality, **<u>after treatment</u>**.
    ☐ Agree
    ☐ Disagree
    ☐ I don’t know

42. At which state of treatment would you prefer to talk about intimacy and sexuality? *(multiple answers possible)*
    ☐ At the same time as the diagnosis breast cancer
    ☐ Before chemotherapy before surgery
    ☐ Before the operation
    ☐ After the operation
    ☐ Before the additional treatment*
    ☐ During the additional treatment
    ☐ At the end of all treatments
    ☐ I don’t want to discuss the subject
    ☐ Other:____________________________

Results of this research

43. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.
    ☐ Yes
    ☐ No

44. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?
    ☐ Yes
    ☐ No

Part 6: Questions about your relationship

If you didn’t have a partner at time of breast cancer or treatment, then you completed the questionnaire.

45. I have a relationship with a:
    ☐ Man
    ☐ Woman

46. Did you have a relationship **before** you were diagnosed with breast cancer?
    ☐ Yes, **go to question 48**
    ☐ No, **go to question 52**

47. Did the **diagnosis breast cancer** had an impact on the quality of the relationship with your partner?
    ☐ Yes, the quality increased
    ☐ Yes, the quality declined
    ☐ Yes, my relationship is broken
    ☐ No, the quality didn’t change

48. Did **body changes** as a result of the breast cancer treatment had an impact on the quality of the relationship with your partner?

- ☐ Yes, the quality increased
- ☐ Yes, the quality declined
- ☐ Yes, my relationship is broken
- ☐ No, the quality didn't change
- ☐ No, my body didn't change

49. Did new complaints on intimacy or sexuality had an impact on the quality of the relationship with your partner?

- ☐ No impact
- ☐ Negative impact
- ☐ Positive impact
- ☐ Inapplicable, I don't had any complaints

50. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?

- ☐ Yes
- ☐ No, but I would have liked to discuss it
- ☐ No, no need to

51. Is it important to you that your partner is present when discussing the subject intimacy and sexuality with a healthcare professional?

- ☐ Yes
- ☐ No

52. Statement: The partner of every breast cancer patient should be offered a conversation about intimacy and sexuality.

- ☐ Agree
- ☐ Disagree
- ☐ I don't know

53. How would your partner support you with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*

- ☐ By exerting as few pressure as possible on sexuality
- ☐ To talk about sexuality
- ☐ To reassure me when a sexual attempt contact fails
- ☐ By not losing intimacy
- ☐ To be involved as much as possible with my sexual complaints
- ☐ By discovering intimacy and sexuality in another wayI don't know
- ☐ Inapplicable, I don't had any complaints
- ☐ Other:____

54. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*

- ☐ To talk about sexuality
- ☐ By not losing intimacy
- ☐ To involve my partner as much as possible by my sexual complaints
- ☐ By discovering intimacy and sexuality in another way
- ☐ Inapplicable, I don't had any complaints
- ☐ I don't know
- ☐ Other:____

55. Would you have liked to receive professional help with complaints on intimacy or sexuality?

☐ Yes
☐ No
☐ Inapplicable, I don’t had any complaints

56. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings					
2. I often take the time to listen to my partner					
3. My partner and I can discuss everything					
4. We try to resolve disagreements with a calm conversation					
5. Disagreements often lead to an argument					
6. My partner tend to boss me					
7. I would like to have sex more often with my partner					
8. My partner and I can talk easily about our sexual desires and needs					
9. I am satisfied with our sex life					
10. I have a good relationship with my partner					
11. I am felling annoyed with my partner					
12. I am happy with my partner					

Thank you for participating in this research.
You can return the questionnaire to attached envelope (no stamp required).

Appendix 6.
Questionnaire chapter 5, part 2

Questionnaire partner (translated from Dutch)

Choose the most suitable answer. Thank you in advance for your effort.

Part 1: demographics

1. What is your age? _____________years

2. What is your ethnicy?
   - ☐ Dutch
   - ☐ Other:____

3. What is your gender?
   - ☐ Male
   - ☐ Female

4. Level of education?
   - ☐ Elementary school
   - ☐ Middle school
   - ☐ High school
   - ☐ College
   - ☐ University
   - ☐ Other:…………………………………….

5. Are you currently employed?
   - ☐ Yes
   - ☐ No, I am in between jobs
   - ☐ No, not able to work due to my illness
   - ☐ No, I am retired
   - ☐ Other:____

Part 2: Diagnosis and treatment

6. Did you already have a relationship **before** she was diagnosed with breast cancer?
   - ☐ Yes, **go to question 7**
   - ☐ No, **go to question 11**

7. To what extent were you concerned about your health when you heard the diagnosis breast cancer?
   - ☐ No concerns
   - ☐ Some concerns
   - ☐ Many concerns
   - ☐ Grave concerns

8. Have your concerns changes **after** treatment?
   - ☐ Yes, my concerns are increased
   - ☐ Yes, my concerns are declined
   - ☐ No, my concerns didn't change
   - ☐ No, I had no concerns

9. Did the **diagnosis breast cancer** had an impact on the quality of the relationship with your partner?
   - ☐ Yes, the quality increased
   - ☐ Yes, the quality declined

☐ Yes, my relationship is broken
☐ No, the quality didn't change

10. Did **body changes** as a result of the breast cancer treatment had an impact on the quality of the relationship with your partner?

☐ Yes, the quality increased
☐ Yes, the quality declined
☐ Yes, my relationship is broken
☐ No, the quality didn't change
☐ No, my body didn't change

11. If your partner is breast cancer-free, are you afraid that the breast cancer may come back?

☐ Inapplicable
☐ Not afraid
☐ A bit afraid
☐ Afraid
☐ Very afraid

Part 3: Your experience about intimacy and sexuality after disease

12. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?

☐ Yes
☐ No, but I would have liked to discuss it
☐ No, no need to

13. Did you experience complaints in intimacy or sexuality before the diagnosis breastcancer?

☐ Yes, **go to question 14**
☐ No, **go to question 17**

14. Did new complaints on intimacy or sexuality had an impact on the quality of the relationship with your partner?

☐ No impact
☐ Negative impact
☐ Positive impact
☐ Inapplicable, I don't had any complaints

15. On a scale of 0-10, in which amount did you suffer from these complaints?

0 means no suffering, 10 means a lot of suffering
Grade: …….

16. To what extent did you find it difficult to handle changes in intimacy and sexuality within your relationship?

☐ No difficulties
☐ A little difficult
☐ Difficult
☐ Very difficult
☐

Part 4: Information about intimacy and sexuality

17. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?

☐ Yes
☐ No

18. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment of your partner?
☐ Yes, **go to question 19**
☐ No, **go to question 23**

19. At what stage did you receive the information about intimacy and sexuality? *(multiple answers possible)*
☐ At the same time as the diagnosis breast cancer
☐ Before chemotherapy before surgery
☐ Before the operation
☐ After the operation
☐ Before the additional treatment*
☐ During the additional treatment
☐ At the end of all treatments
☐ Other: ____

20. Did you have to ask for information about intimacy or sexuality?
☐ Yes, I had to ask for this information by myself
☐ No, the care provider gave the information from
☐ No, it was clear to me where I could find information (for example a flyer or on the web)

21. Who gave you the information about intimacy and sexuality? *(multiple answers possible)*
☐ General practitioner
☐ Surgeon
☐ Nurse on the breast cancer outpatient clinic
☐ Oncologist
☐ Radiotherapist
☐ Plastic surgeon
☐ Psychologist
☐ Sexologist
☐ Social worker
☐ Someone else:____

22. How did you receive information about intimacy and sexuality? *(multiple answers possible)*
☐ Patient flyer
☐ Via other (breast) cancer patients
☐ By an information moment for patients with breast cancer
☐ By Dutch Breast cancer Society (Borstkankervereniging Nederland)
☐ By Dutch Cancer Society (KWF Kankerbestrijding)
☐ By a web page about breast cancer and sexuality
☐ In a conversation with a healthcare professional
☐ Other:____

23. Did you actively searched for information about intimacy and sexuality? *(multiple answers possible)*
☐ No, I didn't searched for information
☐ Yes, on the internet
☐ Yes, via Dutch Breast cancer Society (Borstkankervereniging Nederland)
☐ Yes, Dutch Cancer Society (KWF Kankerbestrijding)
☐ Yes, Via other (breast) cancer patients
☐ Yes, via family or friends
☐ Other:____

24. Are you satisfied with the information about intimacy and sexuality?
    - ☐ Yes, **go to question 26**
    - ☐ No, **go to question 25**
    - ☐ Inapplicable, **go to question 26**

25. What could have been better about the information? *(multiple answers possible)*
    - ☐ The amount was insufficient
    - ☐ The information was too general, it was not about my situation
    - ☐ The content of the information was incorrect
    - ☐ The moment of the information was too late
    - ☐ The moment of informatie was too early
    - ☐ I have asked for information, but I didn't receive any
    - ☐ The healthcare professional should have given me the information
    - ☐ I have no need for information
    - ☐ Other:____

26. What is, according to you, the best way of receiving information about intimacy and sexuality? *(multiple answers possible)*
    - ☐ Patient flyer
    - ☐ Via an application on a tablet or phone (E-health)
    - ☐ By a web page about breast cancer and sexuality
    - ☐ By Dutch Breast cancer Society (Borstkankervereniging Nederland)
    - ☐ By Dutch Cancer Society (KWF Kankerbestrijding)
    - ☐ By a patient forum on the internet
    - ☐ By a group meeting with other patients lead by a healthcare professionals
    - ☐ In a conversation with other (breast) cancer patients
    - ☐ In a conversation with a healthcare professional
    - ☐ None, I have no need for information
    - ☐ Other:____

27. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? *(multiple answers possible)*
    - ☐ At the same time as the diagnosis breast cancer
    - ☐ Before chemotherapy before surgery
    - ☐ Before the operation
    - ☐ After the operation
    - ☐ Before the additional treatment*
    - ☐ During the additional treatment
    - ☐ At the end of all treatments
    - ☐ Other: ____

Part 5: Discussing intimacy and sexuality with a healthcare professional

28. Is it important to you that you are present when the subject intimacy and sexuality is discussed by a healthcare professional?
    - ☐ Yes
    - ☐ No

29. Statement: **<u>The partner</u>** of every breast cancer patient should be offered a conversation about intimacy and sexuality.
    - ☐ Agree
    - ☐ Disagree

☐ I don’t know

30. With which health care professional would you prefer discussing intimacy and sexuality? *(multiple answers possible)*
    - ☐ General practitioner
    - ☐ Surgeon
    - ☐ Nurse on the breast cancer outpatient clinic
    - ☐ Oncologist
    - ☐ Radiotherapist
    - ☐ Plastic surgeon
    - ☐ Psychologist
    - ☐ Sexologist
    - ☐ Social worker
    - ☐ I don’t want to discuss the subject with a health care professional
    - ☐ Other:____

31. At which state of treatment would you prefer to talk about intimacy and sexuality? *(multiple answers possible)*
    - ☐ At the same time as the diagnosis breast cancer
    - ☐ Before chemotherapy before surgery
    - ☐ Before the operation
    - ☐ After the operation
    - ☐ Before the additional treatment*
    - ☐ During the additional treatment
    - ☐ At the end of all treatments
    - ☐ I don’t want to discuss the subject
    - ☐ Other:____________________________

32. Would you have liked to receive professional help with complaints on intimacy or sexuality?
    - ☐ Yes
    - ☐ No
    - ☐ Inapplicable, I don’t had any complaints

Part 6: Questions about your relationship

33. How would your partner support you with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
    - ☐ By exerting as few pressure as possible on sexuality
    - ☐ To talk about sexuality
    - ☐ To reassure me when a sexual attempt Door gerust te stellen als een poging tot seksueel contact fails
    - ☐ By not losing intimacy
    - ☐ To be involved as much as possible with my sexual complaints
    - ☐ By discovering intimacy and sexuality in another wayI don’t know
    - ☐ Inapplicable, I don’t had any complaints
    - ☐ Other:____

34. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
    - ☐ To talk about sexuality
    - ☐ By not losing intimacy
    - ☐ To involve my partner as much as possible by my sexual complaints

☐ By discovering intimacy and sexuality in another way
☐ Inapplicable, I don't had any complaints
☐ I don't know
☐ Other:____

35. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings					
2. I often take the time to listen to my partner					
3. My partner and I can discuss everything					
4. We try to resolve disagreements with a calm conversation					
5. Disagreements often lead to an argument					
6. My partner tend to boss me					
7. I would like to have sex more often with my partner					
8. My partner and I can talk easily about our sexual desires and needs					
9. I am satisfied with our sex life					
10. I have a good relationship with my partner					
11. I am felling annoyed with my partner					
12. I am happy with my partner					

36. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.
☐ Yes
☐ No

37. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?
☐ Yes
☐ No

If you answered 'yes' to question **36 or 37**, you might fill in you contact details. It might take a while before we will contact you. You always can decide not to participate later on.

Name/address/email

Thank you for participating in this research.
You can return the questionnaire to attached envelope (no stamp required).

Appendix 7. Questionnaire chapter 6

Questionnaire medical oncologists (translated from Dutch).

Demographics

1. What is your gender? M/F

2. What is your age? .. . . years

3. What is your function?

   ☐ Oncologist
   ☐ Haematologist
   ☐ Oncologist-in-training (resident)
   ☐ Haematologist-in-training (resident)

4. What is/are your area(s) of specialization?
   ☐ Breast
   ☐ Colorectal
   ☐ Gynaecology
   ☐ Hematology
   ☐ Head and neck
   ☐ Dermatology
   ☐ Lung
   ☐ Lymphoma
   ☐ Nephro- and urology
   ☐ Neuro-endocrine
   ☐ Sarcoma
   ☐ Palliative care
   ☐ Other:……………………………………………..

5. Where do you work?

   ☐ Academic hospital
   ☐ District general teaching hospital
   ☐ District general hospital
   ☐ Cancer institute
   ☐ Academic and district general teaching hospital or district general hospital

6. How long do you practice as an oncologist?

   ☐ < 1 year
   ☐ 1-2 year
   ☐ 3-5 year
   ☐ 6-10 year
   ☐ 11-15 year
   ☐ > 15 year

Sexual function

7. In your current workplace, which percentage of the patients do you estimate to experience changed sexual function due to therapy _________ %

8. How often do you discuss the sexual function of the patient?

☐ Never / almost never
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Almost always / always

9. During the informing of patients about the possible consequences of therapy (informed consent), do you also inform about the possible consequences on sexual functioning?

☐ Never / almost never
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Almost always / always

10. How often do you believe the oncology nurse discusses sexual function with patients?

☐ Never / almost never
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Almost always / always

11. Who has the responsibility for discussing sexual function? (multiple answers possible)
☐ The patient has to raise the subject by itself.
☐ The partner of the patient
☐ Oncologist
☐ Oncology nurse
☐ General practitioner
☐ Social work
☐ Psychologist
☐ Physical therapist
☐ Other: . . ..

If you never discuss sexual function, go to question 22.

12. If you discuss sexual function, with which patients would you do so? (multiple answers possible)
Patients with:

☐ Breast tumours
☐ Colorectal tumours
☐ Gynaecology tumours
☐ Hematology tumours
☐ Head and neck tumours
☐ Skin tumours
☐ Lung tumours
☐ Lymphoma
☐ Nephrologic tumours
☐ Neuro-endocrine tumours
☐ Urologic tumours
☐ Sarcoma
☐ Palliative care
☐ Independent of tumour type
☐ I don’t discuss sexual function
☐ Other:……………………………………………..

13. With which type of treatment patients do you discuss sexual function? (multiple answers possible)

- ☐ Treatment with intent to cure.
- ☐ Life-prolonging treatment.
- ☐ Palliative treatment.
- ☐ Other:………………………………………………………………………….

14. Could you please denote in the subsequent table how often you discuss sexual function with patients from the mentioned age categories?

	Never	**Rarely**	**Regularly**	**Often**
16-35 year				
36-50 year				
51-65 year				
66-75 year				
76 year and older				

15. Which percentage of your patients did you refer in the past year to a physician or other professional for support of sexual problems or for answering question concerning sexual function? ______%

16. How often present patients sexual functioning complaints spontaneously?

- ☐ Never/ rarely
- ☐ In fewer than half of the cases
- ☐ In half of the cases
- ☐ In more than half of the cases
- ☐ Often/ always

17. How often do you make sure that sexual function is discussed with a new patient?

- ☐ Never/ rarely
- ☐ In fewer than half of the cases
- ☐ In half of the cases
- ☐ In more than half of the cases
- ☐ Often/ always

18. How much knowledge do you possess on sexual dysfunction resulting from cancer treatment?

- ☐ No knowledge at all
- ☐ Not so much knowledge
- ☐ Some knowledge
- ☐ Sufficient knowledge
- ☐ A lot of knowledge

19. In which way do you discuss the subject? (multiple answers possible)

- ☐ I don’t ask for it but I tell something about it.
- ☐ Patient raises the subject
- ☐ Addressing possible sexual side effects
- ☐ Closed questions

☐ Open questions
☐ Ask if the patient has questions about it
☐ Use a sense of humour
☐ I hardly or never discuss the subject.

20. If you discuss sexual functioning, what do you ask a female patient? (multiple answers possible)

☐ Fatigue
☐ Fear
☐ Not being able to enjoy
☐ Decreased libido
☐ Insufficient lubrication
☐ Dyspareunia
☐ Reaching an orgasm
☐ Insecurity due to changed self-concept
☐ Insecurity due to changed appearance
☐ Menopause symptoms
☐ Sexual abuse
☐ Other:………………………

21. What do you ask a male patient? (multiple answers possible)

☐ Fatigue
☐ Fear
☐ Not being able to enjoy
☐ Decreased libido
☐ Erectile dysfunction
☐ Reaching an orgasm
☐ Insecurity due to changed self-concept
☐ Insecurity due to changed appearance
☐ Sexual abuse
☐ Other:…………………………..

22. Do you discuss sexual function during follow-up?

☐ Never/ rarely
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Often/ always

23. Do you ever describe phosphodiesterase inhibitor (Viagra or Cialis) to patients with erectile dysfunction?

☐ Never/ rarely
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Often/ always

24. Is in your department sufficient information on sexual function available to provide the patient with?

☐ Yes
☐ No
☐ I don’t know

25. If you discuss sexual function, do you ask for the sexual orientation of the patient? (Homosexual, lesbienne, bisexual?)

☐ Never/ rarely
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Often/ always

26. If you discuss sexual function, do you discuss concerns on 'contagiousness' of cancer during intercourse? (i.e. meaning the transmittance of cancer during intercourse; in case of for example testis-, penis- or cervix tumours)

☐ Never/ rarely
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Often/ always

27. Are problems on sexual function of the patients discussed during the multidisciplinary meetings?

☐ Yes
☐ No

28. Is it from your department or from a protocol an obligation to discuss sexual function at any time?

☐ Yes
☐ No
☐ I don't know

29. Is it from your department clear who is responsible to discuss sexual function with the patient?

☐ Yes
☐ No
☐ I don't know

30. If you discuss sexual function, do you discuss the possible transmitting of chemotherapy agents to the partner during intercourse?

☐ Never/ rarely
☐ In fewer than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Often/ always

31. In the subsequent table are reasons that possibly keep you from discussing sexual function with your patients. To which extent do you agree with the statements? Please circle one square per statement.

	Totally disagree	**Disagree**	**Partly agree/partly disagree**	**Agree**	**Totally agree**
Lack of time					
Lack of knowledge					
Lack of training					
It is someone else's task					

Patient is not ready to discussing sexual health					
Surviving is more important					
Concerned about causing the patient discomfort					
Reasons related to culture/religion					
Reasons related to language/ethnicity					
Age difference between you and patient					
Afraid to offend the patient					
Sexuality is not a patient's concern					
Not relevant for all type of cancers					
Patient is the opposite gender					
No angle or motive for asking					
Embarrassment					
Advanced age of the patient					
Sexuality is a private matter					
I feel uncomfortable					
Patient is too ill					
Patient is the same gender					
Patient doesn't bring up the subject					
No confidence in treatment for sexual dysfunction					
Sexuality is not a matter of life or death					

Colleagues think it is inappropriate if I discuss SF with patients					
Presence of a third party					

32. The oncologist carries responsibility for discussing sexual function with patients.

☐ Totally agree
☐ Agree
☐ Disagree
☐ Totally disagree
☐ I don't know

33. The oncology nurse carries responsibility for discussing sexual function with patients.

☐ Totally agree
☐ Agree
☐ Disagree
☐ Totally disagree
☐ I don't know

34. Do you think it is important to screen for sexual concerns of cancer patients?

☐ Very important
☐ Important
☐ Rather important
☐ Slightly important
☐ Not important

35. With which patients do you believe sexual function should be discussed at least once? (multiple answers possible)
Patients with:

☐ Breast tumours
☐ Colorectal tumours
☐ Gynaecology tumours
☐ Hematology tumours
☐ Head and neck tumours
☐ Skin tumours
☐ Lung tumours
☐ Lymphoma
☐ Nephrologic tumours
☐ Neuro-endocrine tumours
☐ Urologic tumours
☐ Sarcoma
☐ Palliative care
☐ Independent of tumour type
☐ I believe discussing sexual function is not necessary.
☐ Other:……………………………………………..

36. Do you believe there is enough attention for sexual problems and counselling during the current oncology training?

☐ Yes
☐ No

37. Do you feel the need to extent your knowledge on discussing sexual function with your patients?

☐ Yes
☐ No

(Questions on fertility assessment were located in this area but have been removed in this Appendix as they have not been used for this research proposal)

Thank you very much for participating!

Appendix 8.
Questionnaire chapter 7, part 1

Questionnaire AYAs (translated from Dutch).

Part 1: Demographics

1. What is your age? ________ years

2. What is your gender?
   - ☐ Male
   - ☐ Female

3. Are you in a relationship?
   - ☐ No, I am single, continue with question 5
   - ☐ Yes, living apart, continue with question 4
   - ☐ Yes, living together, continue with question 4
   - ☐ Yes, married, continue with question 4
   - ☐ Other, ____

4. If you are in a relationship, for how long? ________ years

5. Do you have children?
   - ☐ Yes
   - ☐ No

6. What is your highest level of education?
   - ☐ None/primary education
   - ☐ Lower vocational education (VMBO/MAVO/LBO)
   - ☐ Intermediate vocational education (MBO)
   - ☐ Higher secondary education (HAVO/VWO)
   - ☐ Higher education (HBO/WO)

7. Do you have a job?
   - ☐ Yes, _______ hours per week (average)
   - ☐ No, job seeking
   - ☐ No, not possible due to illness
   - ☐ No, I am a student
   - ☐ Other, ____

Part 2: Diagnosis and treatment

8. What type of cancer do/did you have?
   - ☐ Brain cancer
   - ☐ Breast cancer
   - ☐ Colorectal cancer
   - ☐ Gynaecological cancer
   - ☐ Hematological cancer
   - ☐ Sarcoma
   - ☐ Skin cancer
   - ☐ Testicular cancer
   - ☐ Thyroid cancer
   - ☐ Other, ____

9. How long ago did you receive your diagnosis?
   - ☐ 0-3 months
   - ☐ 3-6 months

☐ 6 months - 1 year
☐ 1-2 years
☐ 2-4 years
☐ 5-10 years
☐ >10 years

10. How old were you when you received your diagnosis? ______ years

11. What treatments did you undergo? *(multiple answers possible)*
☐ Chemotherapy
☐ Hormonal therapy
☐ Immunotherapy
☐ Operation
☐ Radiotherapy
☐ Other, ____

Part 3: Perception of intimacy and sexuality

12. Did your disease or treatment have a negative influence on your sexuality?
☐ Yes, continue with question 13
☐ No, continue with question 15

13. Which of the items below has (temporarily) influenced your sexuality? *(multiple answers possible)*
☐ Difficulty with orgasm
☐ Emotional lability
☐ Erectile dysfunction
☐ Fatigue
☐ Fear around sex
☐ Fertility issues
☐ Less sexual desire
☐ Lower lubrication
☐ No more pleasure from sex
☐ Pain during intercourse
☐ Scared to disappoint partner
☐ Self-uncertainty due to changed appearance
☐ Self-uncertainty due to changed self-image
☐ Other, ____

14. Do you find it difficult to deal with changes around your sexuality?
☐ Not difficult
☐ Slightly difficult
☐ Difficult
☐ Very difficult

Part 4: Provided information on intimacy and sexuality

15. Do you find it important that good information is available about the possible effects of the treatment on sexuality?
☐ Important
☐ Not important
☐ Impartial

16. Did you ever receive information from a health care professional about the effects of the disease and treatment on sexuality?

☐ Yes
☐ No, continue with question 23

17. At what moment did you receive this information? *(multiple answers possible)*
☐ At the moment of diagnosis
☐ During treatment
☐ After treatment
☐ During follow-up

18. Did you have to ask for this information yourself?
☐ Yes, I had to ask for this information myself
☐ No, the health care professional provided me with this information
☐ No, it was clear to me where to find this information (for example in a folder or on the internet)

19. Which health care professional provided you with the information about intimacy and sexuality? *(multiple answers possible)*
☐ Physician
☐ Nurse practitioner
☐ Nurse in the department
☐ Psychologist
☐ Sexologist
☐ Social worker
☐ Other, ____

20. How did you receive information about intimacy and sexuality? *(multiple answers possible)*
☐ Via a conversation with a health care professional
☐ Via leaflets
☐ Via fellow AYAs
☐ Via an organised meeting at the hospital
☐ Via a general website
☐ Via the AYA website/'Young and Cancer' platform
☐ Via social media
☐ Other, ____

21. Were your parents present when you received information about intimacy and sexuality?
☐ Yes
☐ No, continue with question 23

22. If your parents were present, what did you think of that?
☐ Uncomfortable
☐ Annoying
☐ No problem
☐ Reassuring
☐ Easy
☐ Fine

23. Did you ever actively search for information? *(multiple answers possible)*
☐ No, I did not search for information
☐ Yes, directly via the AYA website (www.aya4net.nl)
☐ Yes, directly via the website www.kankerenseks.nl
☐ Yes, via social media
☐ Yes, via fellow AYAs
☐ Yes, via family/friends/acquaintances
☐ Other, ____

24. What could be improved about the information on intimacy and sexuality? *(multiple answers possible)*

☐ Nothing, I was satisfied with the information
☐ The amount of information did not suffice
☐ The information was too general, it was not about my situation
☐ The content of the information was wrong
☐ The moment of information supply was too late
☐ The moment of information supply was too early
☐ I asked for information, but did not receive any
☐ The health care professional should have provided me with the
☐ information
☐ Other, ____

25. What is, in your opinion, the best way to receive information on intimacy and sexuality? *(multiple answers possible)*

☐ Via leaflets
☐ Via a website
☐ Via (online) videos
☐ Via an online forum or blog
☐ Via group sessions with fellow AYAs, guided by a psychologist
☐ Via an app
☐ Via social media - cross out which you would not use:
☐ Facebook, Instagram, Pinterest, Twitter
☐ Via a conversation with fellow AYAs
☐ Via a conversation with a health care professional
☐ I do not need information
☐ Other, ____

26. What/which moment(s) would, in your opinion, be most suited to receive information about the effects of the disease and treatment on intimacy and sexuality? *(multiple answers possible)*

☐ Before treatment
☐ During treatment
☐ After treatment
☐ 3 months after treatment
☐ 6 months after treatment
☐ 9 months after treatment
☐ 1 year after treatment
☐ Other, ____

Part 5: Addressing intimacy and sexuality with the health care professional

27. Has the subject of intimacy and sexuality sufficiently been discussed by the health care professional?

☐ Yes
☐ No, but I have/had the need to talk about it
☐ No, but I do/did not have the need to talk about it

28. Who is, in your opinion, most suited to discuss intimacy and sexuality with?

☐ My partner
☐ Physician
☐ Nurse practitioner
☐ Nurse in the department
☐ Psychologist
☐ Sexologist
☐ Social worker
☐ I rather discuss it anonymously
☐ Other, ____

29. If intimacy and sexuality were not discussed, what was the reason you did not initiate the conversation with the health care professional yourself? *(multiple answers possible)*

☐ N/A, I did initiate the conversation
☐ I do not want to talk about it
☐ Feeling of shame
☐ Intimacy and sexuality is private
☐ I am too sick to discuss intimacy and sexuality
☐ Nothing can be done about it
☐ Intimacy and sexuality are not my priority
☐ I rather discuss it with my partner
☐ I do not have a partner
☐ The health care professional is too busy
☐ The health care professional does not initiate the conversation
☐ The health care professional does not seem open to this
☐ The health care professional is from the opposite gender
☐ The age of the health care professional
☐ This is no task for the health care professional
☐ Lack of privacy, my partner was present during the conversation
☐ Lack of privacy, my parents were present during the conversation
☐ Lack of privacy, other health care professionals were present during the conversation
☐ Other, _______________________________________

30. Are you satisfied with the information you received on the items below?

Information on..	**Satisfied**	**Impartial**	**Dissatisfied**	**Not received**
Consequences of treatment on sexuality				
Where to find relevant information				
How to deal with sexual issues				
Which health care professional to approach in case questions occur				
Professional help with sexual issues				
Sexual tools				
Information for partners				
Other suggestions:				

31. For which of the items below do you find the availability of information important?

Information on..	**Important**	**Impartial**	**Not important**
Consequences of treatment on sexuality			
Where to find relevant information			
How to deal with sexual issues			
Which health care professional to approach in case questions occur			
Professional help with sexual issues			
Sexual tools			
Information for partners			
Other suggestions:			

Part 6: Relationships

32. Are you currently in a relationship?

☐ Yes, continue with question 35
☐ No, continue with question 33

33. Does the disease have an impact on starting a new relationship?

☐ Yes
☐ No
☐ I don't know

34. Do problems or uncertainty with fertility have an impact on starting a new relationship?

☐ Yes
☐ No
☐ I don't know

If you did not have a partner at the moment of diagnosis or during treatment, you are now finished with the questionnaire.

35. Were you in a relationship at the moment of diagnosis?

☐ Yes, continue with question 36
☐ No, continue with question 38

36. Did sexual problems, as a result of the diagnosis or treatment, influence your relationship with your partner?

☐ No influence
☐ Negative influence
☐ Positive influence
☐ N/A, I do not experience sexual problems

37. Have you discussed possible effects of the cancer treatment on intimacy and sexuality with your partner?

☐ Yes
☐ No, because ___________________________________
☐ No, there is no need of

38. Do you find it important to have your partner present when discussing intimacy and sexuality with a health care professional?

☐ Yes
☐ No
☐ I don't know

39. Is there enough information about intimacy and sexuality available for partners?

☐ Yes
☐ No
☐ I don't know

Thank you very much for participating!
You can find more information on this subject via https://sickandsex.nl

Appendix 9.
Questionnaire chapter 7, part 2

Questionnaire healthcare professionals (translated from Dutch).

Part 1: Demographics

1. What is your gender?
   - ☐ Male
   - ☐ Female

2. What is your age? ________ years

3. What is your function?
   - ☐ Medical specialist
   - ☐ Oncologist/internist-in-training (resident)
   - ☐ Nurse specialized in AYA care
   - ☐ Nurse practitioner
   - ☐ Oncology nurse
   - ☐ Social worker
   - ☐ Other, ____

4. Time of practice in the area of oncology, including your education?
   - ☐ 0-11 months
   - ☐ 1-2 years
   - ☐ 3-5 years
   - ☐ 6-10 years
   - ☐ 11-15 years
   - ☐ >15 years

5. Where do you work? *(multiple answers possible)*
   - ☐ Academic hospital
   - ☐ General teaching hospital
   - ☐ District general hospital
   - ☐ Independent extramural practice
   - ☐ Extramural group practice
   - ☐ Other, ____

6. Did you follow a course/training on sexuality in AYAs or oncology patients in general?
   - ☐ Yes, specifically for AYAs
   - ☐ Yes, on cancer and sexuality in general
   - ☐ No

Part 2: The discussion of sexuality with AYAs

7. How often do you discuss sexuality with a new AYA?
   - ☐ Never
   - ☐ In less than half of the cases
   - ☐ In half of the cases
   - ☐ In more than half of the cases
   - ☐ Always

8. How often do you discuss sexuality with an AYA during follow-up?

☐ Never
☐ In less than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Always

9. Can you mark in the table below how often you discuss sexuality in the following age categories:

	Never	**In less than half of the cases**	**In half of the cases**	**In more than half of the cases**	**Always**
18 years					
19 – 25 years					
25 – 30 years					
> 30 years					

10. Can you mark in the table below how often you discuss sexuality with:

	Never	**In less than half of the cases**	**In half of the cases**	**In more than half of the cases**	**Always**
Male patients					
Female patients					

11. Can you mark in the table below how often you discuss sexuality in the following AYA subgroups:

	Never	**In less than half of the cases**	**In half of the cases**	**In more than half of the cases**	**Always**	**N/A, I don't see these patients**
Brain cancer						
Breast cancer						
Colorectal cancer						
Gynaecological cancer						
Hematological cancer						
Sarcoma						
Skin cancer						
Testicular cancer						

Thyroid cancer						

12. Can you mark in the table below how often you discuss sexuality with patients:

	Never	**In less than half of the cases**	**In half of the cases**	**In more than half of the cases**	**Always**
In curative setting					
In palliative setting					
In terminal setting					

13. Do AYAs present sexual questions or complaints on their own initiative?

☐ Never
☐ In less than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Always

14. If you discuss sexuality with an AYA, how do you do this?

☐ I do not/rarely discuss sexuality
☐ I discuss this during the first consult
☐ I discuss this during a follow-up consult
☐ I make a separate appointment
☐ Someone else from the treatment team usually discusses this
☐ I refer someone
☐ Other, ____

15. If you discuss sexuality, how often do you discuss this when the AYAs' parents are present?

☐ I do not/rarely discuss sexuality
☐ Never
☐ In less than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Always

16. Do you find it important to have the partner present when discussing sexuality?

☐ Yes, I always ask the partner to attend the conversation
☐ I leave the choice with the patient and/or partner
☐ No, I prefer to discuss this separately with the patient
☐ No, I do not/rarely discuss sexuality
☐ Other, ____

17. Do you discuss the influence of the disease on the relationship between the AYA and partner?

☐ Never
☐ In less than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Always

18. If you discuss sexual functioning with a **man**, what do you discuss? *(multiple answers possible)*

☐ Difficulty with orgasm
☐ Emotional lability
☐ Erectile dysfunction
☐ Fatigue
☐ Fear around sex
☐ Hormonal changes
☐ Less sexual desire
☐ No more pleasure from sex
☐ Pain during intercourse
☐ Self-uncertainty due to changed appearance
☐ Self-uncertainty due to changed self-image
☐ Side-effects of medication
☐ Other, ____

19. If you discuss sexual functioning with a **woman**, what do you discuss? *(multiple answers possible)*

☐ Difficulty with orgasm
☐ Emotional lability
☐ Fatigue
☐ Fear around sex
☐ Hormonal changes
☐ Less sexual desire
☐ Lower lubrication
☐ No more pleasure from sex
☐ Pain during intercourse
☐ Self-uncertainty due to changed appearance
☐ Self-uncertainty due to changed self-image
☐ Side-effects of medication
☐ Other, ____

20. The list below shows a number of reasons that may prevent you from discussing sexuality with patients. To which extent do you agree with the statements? Please mark one square per statement.

	Totally disagree	**Disagree**	**Partly agree/partly disagree**	**Agree**	**Totally agree**
Lack of time					
Lack of knowledge					
Lack of training					
It's someone else's task					
AYA is not ready to discuss sexuality					
Sexuality is not a patient's concern					
AYA is too ill					

Reasons related to culture/religion					
Reasons related to language/ethnicity					
AYA's parents are present					
AYA's partner is present					
Age difference between you and AYA					
Sexuality is a private matter					
Presence of a third party					
AYA is the opposite gender					
I feel uncomfortable					
Afraid to offend the AYA					
Not feeling a connection with the AYA					
No angle or reason for asking					
AYA doesn't bring up the subject					
AYA doesn't have a partner					
No resources to refer the AYA					
My workplace is not quiet					

21. Is there a protocol from your centre where the discussion of sexuality is included?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

22. Is it from your department clear who is responsible for discussing sexuality with the AYA?
    - ☐ Yes, namely ___________________________________
    - ☐ No
    - ☐ I don't know

23. Is in your current workspace sufficient information available on sexuality to provide the AYA with?

☐ Yes
☐ No

24. Which percentage of the AYAs did you refer in the past year to a physician or other health care professional for support of sexual problems? ________ %

25. If you refer an AYA for support of sexual problems, to whom do you refer them?

☐ I never refer an AYA
☐ Oncologist/head practitioner
☐ Urologist
☐ Gynaecologist
☐ Sexologist
☐ Psychologist
☐ Nurse
☐ General practitioner
☐ Other, ____

Part 3: Knowledge about sexual changes due to treatment

26. Do you think it is important to discuss the influence of treatment on sexuality?

☐ Very important
☐ Important
☐ Slightly important
☐ Not important

27. Has the subject of sexuality in AYAs been addressed during your education?

☐ Yes
☐ No

28. Has the subject of sexuality ever been discussed during in-service training?

☐ Never
☐ Rarely
☐ Regularly
☐ Often

29. To which extend do you possess sufficient knowledge to be able to discuss sexuality with an AYA?

☐ No knowledge at all
☐ Not so much knowledge
☐ Some knowledge
☐ Sufficient knowledge
☐ A lot of knowledge

30 Do you feel capable to discuss sexuality with AYAs?

☐ Yes
☐ No

30. Do you feel the need to extent your knowledge on discussing sexuality with AYAs?

☐ Yes
☐ No

31. What could be helpful to discuss sexuality with AYAs? *(multiple answers possible)*

☐ Training to improve skills on discussing sexuality
☐ Leaflets about sexuality to give to the AYA
☐ A short line with department of sexology for easy referral
☐ Clear guidelines or protocols on which health care professional discusses sexuality
☐ More time with the patient
☐ Quiet workplace
☐ Other, ______________________________________

Part 4: Opinion on discussing sexuality

32. Who has, in your opinion, the responsibility for discussing sexuality? *(multiple answers possible)*
☐ The AYA
☐ Partner of the AYA
☐ Head practitioner/medical specialist
☐ Nurse specialized in AYA care
☐ Social worker
☐ Radiotherapist
☐ General practitioner
☐ Sexologist
☐ Psychologist
☐ Other, ______________________________________

33. Do you think it is important to inform AYAs about potential sexual dysfunction due to treatment?
☐ Very important
☐ Important
☐ Slightly important
☐ Not important

34. Do you think it is important to screen AYAs for sexual dysfunction?
☐ Very important
☐ Important
☐ Slightly important
☐ Not important

35. How often do you discuss fertility with AYAs?
☐ Never
☐ In less than half of the cases
☐ In half of the cases
☐ In more than half of the cases
☐ Always

36. To which extend do you possess sufficient knowledge to be able to discuss fertility with an AYA?
☐ No knowledge at all
☐ Not so much knowledge
☐ Some knowledge
☐ Sufficient knowledge
☐ A lot of knowledge

37. Has the subject of fertility in AYAs been addressed during your education?
☐ Yes
☐ No

38. Do you feel capable to discuss fertility with AYAs?
   - ☐ Yes
   - ☐ No

Thank you very much for participating!
You can find more information on this subject via https://sickandsex.nl

Appendix 10. Supplementary to chapter 8: Table S1

TABLE S1 Semi-structured interview questions used for interviews with participants

Number	Question
1	I want to start this interview with the question of what oral information provision on intimacy and sexuality for AYA patients currently looks like in your practice?
2	Ideally, what should oral information provision on intimacy and sexuality for AYA patients in your opinion looks like in the future?
3	What gaps or barriers do you currently notice in oral information provision and how could these ideally be solved?
4	Literature shows barriers in communication about intimacy and sexuality as well, like … (lack of knowledge/experience having the conversation, lack of resources/referrals for patients, low priority, presence of parents/family, patients discomfort, clinicians discomfort, time and a lack of rapport/longitudinal relationship), how could these ideally be solved?
5	Ideally, who should discuss the topic intimacy and sexuality with AYA patients?
6	When should the topic intimacy and sexuality ideally be discussed with AYA patients?
7	In terms of content, what should ideally be discussed with AYA patients in the topic intimacy and sexuality?
8	How does education material on intimacy and sexuality for AYA patients currently looks like in your practice?
9	Do you feel a certain need in education material around intimacy and sexuality for AYAs?
10	Ideally, what should information material on intimacy and sexuality for AYA patients in your opinion looks like in the future?
11	In terms of content, what should the information material on intimacy and sexuality ideally contain for AYAs?

Appendix 11. Supplementary to chapter 9: S1

Search in PubMed. Search date: 11 October 2019. Limitations: English language.

(neoplasms[majr] OR "Cancer Survivors"[majr] OR cancer*[ti] OR adenoma*[ti] OR adenocarcinom*[ti] OR anticarcinogen*[ti] OR antitumour*[ti] OR blastoma*[ti] OR carcinogen*[ti] OR carcinom*[ti] OR carcinosarcoma*[ti] OR chordoma*[ti] OR germinoma*[ti] OR gonadoblastoma*[ti] OR hepatoblastoma*[ti] OR hodgkin disease[ti] OR hodgkin's disease[ti] OR hodgkins disease[ti] OR leukemi*[ti] OR lymphangioma*[ti] OR lymphangiomyoma*[ti] OR lymphangiosarcoma*[ti] OR lymphom*[ti] OR malignan*[ti] OR maligne[ti] OR malignes[ti] OR melanom*[ti] OR meningioma*[ti] OR mesenchymoma*[ti] OR mesonephroma*[ti] OR metasta*[ti] OR neoplas*[ti] OR neuroma*[ti] OR nsclc[ti] OR oncogen*[ti] OR oncolog*[ti] OR paraneoplastic[ti] OR plasmacytoma*[ti] OR precancerous[ti] OR sarcoma*[ti] OR teratocarcinoma*[ti] OR teratoma*[ti] OR tumor[ti] OR tumors[ti] OR tumour*[ti]) AND ("Sexual Dysfunctions, Psychological"[majr] OR "Sexual Behavior"[majr] OR "Sexual Partners"[majr] OR "Sexual Dysfunction, Physiological"[majr] OR "Sexual Health"[majr] OR "Orgasm"[majr] OR "Coitus"[majr] OR sex[ti] OR sexual*[ti] OR orgasm[ti] OR orgasms[ti] OR erection[ti] OR erections[ti] OR erectile[ti] OR coitus[ti] OR intercourse[ti] OR "Sex Education"[majr] OR "Sex Counseling"[majr]) AND ("Education"[majr] OR educat*[ti] OR workshop*[ti] OR train[ti] OR training*[ti] OR trained[ti] OR program[ti] OR programs[ti] OR teach[ti] OR teached[ti] OR teaching[ti] OR intervention*[ti] OR course[ti] OR courses[ti] OR "Learning"[majr] OR learn[ti] OR learned[ti] OR learning[ti] OR knowledge[ti] OR "Role Playing"[majr] OR role play*[ti] OR quality improve*[tw] OR "improving quality"[tw] OR "improving the quality" [tw] OR supportive car*[tw] OR support car*[tw] OR physician discussion*[tw] OR physicians discussion*[tw] OR physician's discussion*[tw] OR (quality[ti] AND improv*[ti])) AND (English[lang] OR Dutch[lang])
333 (11 okt 2019)

Appendix 12. Supplementary to chapter 9: S2

Assessment of risk of bias in individual studies according to the JBI -MAStARI Critical appraisal checklist

JBI -MAStARI Critical appraisal checklist (items 1-13) for randomized Controlled Trials	Kim (2014)	JBI -MAStARI Critical appraisal checklist for Quasi-Experimental Studies (items 1-9).	Jonsdottir (2016)	Wang (2015)	Reese (2019)	Afiyanti (2016)	Hordern (2009)	Grondhuis (2019)
1. Was true randomization used for assignment of participants to treatment groups?	Y	1. Is it clear in the study what the cause is and what the effect?	Y	Y	Y	Y	Y	Y
2. Was allocation to treatment groups concealed?	Y	2. Were the participants included in any comparisons similar?	Y	Y	Y	Y	Y	N
3. Were treatment groups similar at baseline?	Y	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Y	Y	Y	Y	Y	Y
4. Were participants blind to treatment assignment?	N	4. Was there a control group?	N	N	N	N	N	N
5. Were those delivering treatment blind to treatment assignment?	N	5. Were there multiple measurements of the outcome both pre- and post- the intervention/exposure?	Y	Y	Y	Y	Y	Y

Continuation **S2**

6. Were outcomes assessors blind to treatment assignment?	N	6. Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?	Follow-up incomplete, although adequately described and analyzed	Follow-up incomplete, although adequately described and analyzed	Y	Y	Follow-up incomplete, although	Follow-up incomplete, although adequately
7. Were treatment groups treated identically other than the intervention of interest?	Y	7. Were the outcomes of participants included in any comparisons measured in the same way?	Y	Y	Y	Y	Y	Y
8. Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?	Y	8. Were outcomes measured in a reliable way?	Y	Y	Y	Y	Y	Y
9. Were participants analyzed in the groups to which they were randomized?	Y	9. Was appropriate statistical analysis applied?	Y	Y	Y	N	Y	Y
10. Were outcomes measured in the same way for treatment groups?	Y							

Continuation **S2**

11. Were outcomes measured in a reliable way?	Y
12. Was appropriate statistical analysis used?	Y
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Y

List of publications

Van Doorn T, Albers LF, van der Laan J, Roshani H. Paraganglioma of the bladder: a case report. SN Comprehensive Clinical Medicine 2021 (in press)

Albers LF, Tillier CN, Muilekom HAM, Elzevier HW, van Rhijn BW, Van der Poel HG, Hendricksen K. Sexual satisfaction in men suffering from erectile dysfunction after robot assisted radical prostatectomy for prostate cancer: an observational study. Journal of Sexual Medicine 2020 Dec 24

Albers LF, van Belzen MA, van Batenburg C, Engelen V, Putter H, den Ouden MEM, Pelger RCM, Elzevier HW. Sexual health care for intimate partners of people with cancer: information and communication needs: a brief communication. J Sex Marital Ther. 2020

Albers LF, Grondhuis Palacios LA, Pelger RCM, Elzevier HW. Can the provision of sexual healthcare for oncology patients be improved? A literature review of educational interventions for healthcare professionals. J Cancer Surviv. 2020 Jun 1

Albers LF, Bergsma FB, Mekelenkamp H, Pelger RCM, Manten-Horst E, Elzevier HW. Discussing sexuality with adolescent and young adults with cancer: a qualitative study among internist and nurses. J Cancer Educ. 2020 Jun 17

Albers LF, Elzevier HW. Jongvolwassenen en hun zorgverleners denken verschillend over het bespreekbaar maken van intimiteit en seksualiteit. Nederland Tijdschrift voor Psychosociale oncologie. 2020. 28:1.

Albers LF, van Belzen MA, van Batenburg C, Engelen V, Putter H, Pelger RCM, Elzevier HW. Discussing sexuality in cancer care: towards personalized information for cancer patients and survivors. Support Care Cancer. 2020 Jan 03

Albers LF, van EK GF, Krouwel EM, Oosterkamp-Borgelink CM, Liefers GJ, Den Ouden MEM, Den Oudsten BL, Krol-Warmerdam EEM, Guicherit OR, Putter H, Pelger RCM, Elzevier HW. Sexual health needs: how do breast cancer patients and their partners want information? J Sex Marital Ther. 2019 Nov 25:1-22

Albers LF, Haj Mohammad SF, Husson O, Putter H, Pelger R.C.M., Elzevier H.W., Manten-Horst E. Exploring communication about intimacy and sexuality: what are the preferences of adolescents and young adults with cancer and their healthcare professionals? J Adolesc Young Adult Oncol. 2019 Oct 31

Krouwel EM, Albers LF (shared first authorship), Nicolai MPJ, Putter H, Osanto S, Pelger RCM, Elzevier HW. Discussing Sexual Health in the Medical Oncologist's Practice: Exploring Current Practice and Challenges. J Cancer Educ. 2019 Jun 17.

Albers LF, Korving JC, van Elzakker EPM, Roshani H. Osteomyelitis of the pubic symphysis after transrectal biopsies of the prostate. Urology, 2018 Jun 21.

Albers LF, Van Ek GF, Krouwel EM, Elzevier HW. Toward implementation of sexual healthcare. Gynecologic Oncology Reports. 2017.

Albers LF. Gamers join real-life fight against malaria and tuberculosis. The Lancet Infectious Diseases. 2016: 16(4): 418.

Albers LF, Van Roosmalen JJM, Tura AK. Climate change and neonatal survival: the case of Ethiopia. The Lancet Global Health. 2016: 4(4): 236.

Albers LF. Merkloze sigarettenpakjes: in Nederland nog niet aan de orde. Ned Tijdschr Geneeskd. 2015; 159:C2615.

Curriculum Vitae

Leonore Frederique Albers was born in Capelle aan den IJssel, the Netherlands on January 19th, 1992. She graduated cum laude from Emmauscollege in Rotterdam in 2010. She continued with medical school at University of Leiden in the same year. After obtaining her bachelor's degree in 2013, she paused her study for one year to be chairman of the Royal Student Rowing Club "Njord", where she had been rowing during her bachelor. After this year she did an internship at the Dutch Journal of Medicine in Amsterdam and at The Lancet in London in 2015 where her scientific interest started.

During her internship surgery, she became interested in urology, resulting in a scientific internship urology at the Leiden University Medical Center (LUMC) and a senior internship urology at the HagaZiekenhuis. In December 2017 she obtained her medical degree cum laude and started working as a junior clinical fellow (ANIOS) at the department of urology at the Amsterdam University Medical Center (location AMC). In 2019 she continued her scientific research at the department urology of the LUMC under supervision of prof. dr. Pelger and dr. Elzevier. She collaborated with the Netherlands Cancer Institute – Antoni van Leeuwenhoek under supervision of dr. Hendricksen. During her PhD she worked two periods parttime as junior clinical fellow (ANIOS) at the urology department of the LUMC. Leonore got accepted to a research fellowship at the department of Urology at Memorial Sloan Ketting Cancer Center (New York, USA) under supervision of dr. J.P. Mulhall. Unfortunately, this was cancelled due to the COVID-19 pandemic.

Currently, Leonore lives in Amsterdam. She recently started with her general surgery residency at the Onze Lieve Vrouwe Gasthuis under the supervision of dr. Gerhards (as part of urology residency). In 2023 she will continue her urology residency in the LUMC.

Dankwoord

Prof. dr. Pelger, Rob, bedankt voor de kans om promotieonderzoek te kunnen doen. Uw werksnelheid is indrukwekkend!

Dr. Elzevier, beste Henk, bedankt voor je eindeloze ideeën en energie. Het vertrouwen, me vrijlaten en in m'n kracht zetten. En het inzicht dat chaos tot de beste ideeën leidt.

Prof. dr. Putter, dank voor alle hulp en inzichten in de statistiek.

Urologen, arts-assistenten, verpleging van de urologie uit het LUMC; bedankt voor alle kansen, de leerzame en leuke tijd. Esmee, Gaby; mede door jullie dit boekje! Caroline: bedankt voor je ondersteuning en luisterend oor. Tot 2023!

Dr. Hendricksen, andere urologen en onderzoekers uit het Antoni van Leeuwenhoek. Wat een waardevolle toevoeging aan mijn promotieonderzoek dat ik bij jullie mocht komen. De combinatie van jullie kritische en enthousiaste houding zie ik als een groot voorbeeld.

NFK, AYA netwerk, Groene Hart Ziekenhuis, HMC; bedankt voor de goede samenwerking!
En wetenschapsstudenten: bedankt voor jullie bijdrage aan mijn proefschrift. Het was me een genoegen om jullie te mogen begeleiden!

Urologen, arts-assistenten, onderzoekers en andere collega's uit het AUMC, locatie AMC; bedankt voor de begeleiding bij de eerste klinische stappen binnen de urologie. Ik heb het zo naar mijn zin gehad.

Stichting Medical Business, wat een mooie club mensen en een geweldige plek om te mogen leren naast studie en werk. Zoveel energie en enthousiasme, stevige discussies en heerlijke (ski)weekendjes weg.

Lieve vrienden, jullie weten zelf wie! Deze pagina is te kort..wat een geluk heb ik met jullie om me heen. Bedankt voor al het lachen, gezelligheid, warmte, feestjes, goede gesprekken, ontelbare trainingsuren op het water, op de fiets of de schaatsen en jullie eindeloos brede schouders op te steunen!

Floris, dankjewel dat je er altijd voor me bent.

Loes, Sandra; wat is het (Amsterdamse) leven een feest met jullie! Ik koester onze mooie vriendschap en parrhesia.

Mireille, meer dan 15 jaar vriendinnen. Bedankt dat je altijd voor me klaar staat. Allebei onze eigen weg en toch altijd samen. En nu tegelijk in opleiding; het moest zo zijn.

Papa, mama, Tijmen; bedankt voor de onbezorgde jeugd en onvoorwaardelijke steun en liefde. Bedankt dat ik altijd mijn eigen pad kon kiezen.

Lieve Maurits, wat voelt het goed. Ben zo gek op jou! Ik kijk uit naar de toekomst met jou.