



Universiteit
Leiden
The Netherlands

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>

Version: Publisher's Version

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

Downloaded from: <https://hdl.handle.net/1887/3151775>

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

Cover Page



Universiteit Leiden



The handle <http://hdl.handle.net/1887/3151775> holds various files of this Leiden University dissertation.

Author: Albers, L.F.

Title: Cancer and sexual health: The continuum of care

Issue date: 2021-04-07

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)	Partners (n=76)
	n (%)	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. IARC. 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, Illaramendi 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, Ponzzone 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, Bhamra 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, Sufirin 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, Tulsy 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, Schaliij 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

