Cancer and sexual health: The continuum of care

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

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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 n (%)	Partners n (%)	p-value
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.

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