



Intimacy and sexuality in women with breast cancer: professional guidance needed

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Received: 15 February 2018 / Accepted: 16 October 2018
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Abstract

Background Approximately 60–70% of breast cancer survivors experience sexuality problems resulting from treatment. This study investigated information and communication preferences with professionals on the topic intimacy and sexuality of women diagnosed with breast cancer.

Methods Members of the Dutch Breast Cancer Patient Association were surveyed regarding their experiences and preferences about information on intimacy and sexuality. An online questionnaire was developed that included five close-ended and one open-ended question regarding: information received; type of professional preferred; method and timing of communication on the topics of intimacy and sexuality. Quantitative data were analysed using descriptive statistics. A deductive framework analysis was performed on the open-ended answers to enrich the data of the close-ended questions.

Results In total, 667 female breast cancer (ex-)patients participated. In 46% of the women, the information received matched their needs. Most women preferred to receive information about the impact on intimacy and sexuality from a nurse (66.4%) or primary doctor (27.9%). The preferred method of communication was a conversation with a professional together with their partner (51.6%) or a personal conversation with a professional. Respondents emphasized the importance of appropriate timing of information, preferably at least shortly after the treatment started (45.1%).

Conclusions This study shows that intimacy and sexuality should be repeatedly included in consultations, at every stage of the disease but especially shortly after treatment started. Women with breast cancer expect that professionals (preferably nurse or primary doctor) initiate this subject via a personal conversation (alone or with their partner).

Keywords Breast cancer · Communication · Intimacy · Oncology · Sexuality

Background

Breast cancer is the most common type of cancer among women, with approximately 1.67 million cases diagnosed annually worldwide. Breast cancer covers 25% of all cancer incidence ratio's amongst women [1]. In the Netherlands, the incidence of breast cancer has stabilised [2], which is comparable with trends of other western European countries [3].

Breast cancer is the number one in prevalence amongst women; it is ranked second in mortality rates, after lung cancer. The survival rate improved during the last decades due to better treatment options and large-scale screening programmes [4]. However, survivors experience a number of side effects and decreased quality of life after treatment [5].

One of the affected aspects of quality of life are sexuality related complaints [6]. Previous studies showed that approximately 60–70% of breast cancer survivors experience problems related to sexuality [5, 7]. These sexuality problems are related to body image, sexual activity (e.g. lubrication, orgasm) and sexual functioning (e.g. sexual arousal, sexual desire and sexual pleasure) [8, 9]. These result from chemotherapy, chemically induced menopause, tamoxifen, and breast cancer surgery [10].

The sexuality related problems could also affect the intimacy and relationship of women with breast cancer [11]. Both women with breast cancer and their partners need to

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s12282-018-0927-8>) contains supplementary material, which is available to authorized users.

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cope with the physical, psychological and social changes due to breast cancer [12]. Effective communication with professionals and partner seems to play an essential role in the coping process [13]. Open and constructive communication instead of pressured and withdrawn communication is likely to be beneficial to (preventing) sexual problems [14]. Furthermore, professionals play an important role in the communication about intimacy and sexuality. Research shows that acknowledging sexual changes, while providing health information and supportive interventions, is significant to patients [15]. Kedde et al. showed that in only half of women with breast cancer ($n = 345$) changes in sexuality had been mentioned during consultations with a professional, mostly on the initiative of the healthcare professional [8]. Moreover, only 40% of the women that wanted care for sexual dysfunction consulted a healthcare professional [8]. However, little information is available about appropriate modes of communication. The aim of the present study is to investigate the information and communication preferences with professionals on the topics of intimacy and sexuality of women diagnosed with breast cancer.

Methods

Study population and data collection procedure

The study population consisted of members of the Dutch Breast Cancer Patient Association, known as ‘Borstkankervereniging Nederland’ (BVN). BVN is a nationwide patient organisation exclusively for breast cancer patients and their relatives, with more than 6000 members, aiming to optimize quality of care and quality of life for this patient group. B-force with approximately 1800 members is part of BVN and functions as online platform. The members are mainly women (99%), with a mean age of 54 years (standard deviation 10 years). Eighty-two percent are (ex)breast cancer patient, 8% of the members have metastasized breast cancer, 3% have a (possible) non-invasive breast cancer (ductal carcinoma in situ), 5% have a BRCA gene mutation (no cancer) and 2% ‘other’ (e.g. medical specialists) [16]. B-force regularly invites patients and other applicants to share their opinions, experiences and perceptions. For this study, all B-force members were invited to fill-out a short online questionnaire (inclusion criterium). There were no explicit exclusion criteria for respondents. However, for the present analyses, men with breast cancer were excluded ($n = 2$) due to the small number of men participating.

The online questionnaire about the impact of breast cancer on sexuality and intimacy was open for response in December 2014 for 2 weeks. To comply with the right not to participate we did not send a reminder during this time frame. Questions were completed anonymously, as

guaranteed by B-force. No ethical approval was required, as this study was not part of the Medical Research Involving Human Subjects Act. Confidentiality issues were dealt with according to the Dutch law (Personal Data Protection Act). Data were anonymized from the moment participants filled out the questionnaire and data were stored at a secured folder at the university of applied science.

Questionnaire on intimacy and sexuality

Respondents were asked to fill out personal characteristics such as gender, year of birth, and year of diagnosis. Some information about patient characteristics was missing, as filling out respondent characteristics was not conditional for completing the survey.

The questionnaire (see Appendix I) included five multiple-choice questions regarding: (1) perceived problems concerning intimacy and sexuality; (2) information that was received regarding intimacy and sexuality related problems that could arise; (3) the preferred professional to receive information from; (4) the preferred method of communication (e.g. personal communication, book, social media); (5) the preferred timing of communication. For each question, the respondents could select multiple answers. The questionnaire was ended with a section where respondents could share additional information regarding ‘intimacy, sexuality and breast cancer’ in a free text box.

Data-analysis

The first phase comprised analysis of close-ended questions. Quantitative data derived from the multiple-choice questions were analysed using descriptive statistics for describing characteristics of respondents and reporting multiple-choice outcomes. There was no missing data. These analyses were performed using IBM SPSS Statistics (version 22).

In the second phase, responses on the open-ended question were analysed. A first check of the additional information provided by respondents in the free text box revealed that these responses were of significant additional value to the research question of this paper (MPK and HdV). As such, these responses provided valuable in-depth insights in addition to the quantitative data generated by the multiple-choice close-ended questions. First, MPK and HdV screened responses to include in the open-ended questions qualitative dataset. It was sufficient for one researcher to find a response relevant for a certain multiple-choice question to include the response in the data set of that question. No consensus was required at this stage as the aim was to get a rich data set per question.

Consequently, a deductive framework analysis (guided by the questions of the questionnaire) was performed on the additional information provided by the respondents using

Atlas.ti software [17]. First, two researchers coded the responses independently. Second, consensus was achieved by discussion until both researchers (MdO and MPK) agreed on the meaning of the codes that would best cover the according quotations [18]. The analysis was sent to program manager and project leader of the Dutch Breast Cancer Patient Association to increase the validity of the qualitative analysis and concept of the manuscript.

Results

The online questionnaire was completed by 667 patients and ex-patients, with a mean age of 55 years (sd 9 years). The study population included female patients and ex-patients. On average, breast cancer was diagnosed 5 years ago (sd 4.6 years).

Information needs

Two-thirds ($n=452$) of the respondents experienced sexuality problems due to breast cancer (Table 1), mainly due to physical (49.6%) or a combination of physical and psychological problems (27.9%). The other respondents did not experience problems regarding sexuality ($n=148$) or the topic was not applicable for them (e.g. not sexually active) ($n=73$).

Almost 60% of the respondents would have preferred to receive information about the effects of breast cancer (treatment) on intimacy and sexuality, although 40.0% of them did not receive this information (Table 2). On the other hand, 41.2% of the respondents did not want to receive information, of which 27.0% also did not receive information about intimacy and sexuality. In 45.7% of the women the information received matched their needs.

Table 1 Problems regarding intimacy and sexuality due to breast cancer ($n=667$)

Responses	<i>n</i> (%)
Sexuality problems	452 (67.8)
Caused by physical problems	224 (49.6)
Caused by psychological problems	41 (9.1)
Caused by relationship problems	19 (4.2)
Caused by physical and psychological problems	126 (27.9)
Caused by physical and relationship problems	9 (2.0)
Caused by psychological and relationship problems	12 (2.7)
Caused by physical, psychological and relationship problems	21 (4.6)
No problems experienced	148 (22.2)
Not sexually active anymore	32 (4.8)
Not applicable for other reasons	41 (6.1)

Table 2 Preferred and perceived information about breast cancer treatment and the preferred timing of communication ($n=667$)

	<i>n</i> (%)
Information	
No information received and did not want information	180 (27.0)
No information received but wanted information	267 (40.0)
Received information but did not want information	95 (14.2)
Received information and wanted information	125 (18.7)
Preferred timing of information	
Before treatment(s)	257 (38.6)
During treatment(s)	185 (27.7)
Within 6 months after treatment(s) started	301 (45.1)
Six months or more post treatment(s)	161 (24.1)
I do not know/not applicable	111 (16.6)

Communication about the impact of breast cancer (treatment) requires more than only mentioning the possible changes, it can prepare patients and their partners to deal with the possible changes in intimacy and sexuality. Women would like to receive information with regard to intimacy and sexuality, to be better prepared for the possible physical, psychological and relational changes. Consequently, women may not feel that “they are one of few who experience these problems” (55-year-old woman) and “they feel insecure and less of a woman” (65-year-old woman).

Preferred timing

In the open-ended question, respondents emphasised the importance of appropriate timing of information. However, they differ in their opinion regarding to what the appropriate time is: ‘within six months’ after treatment(s) (45.1%) ‘before’ treatment(s) (38.6%), ‘during’ treatment(s) (27.7%), as well as ‘six months or more’ post treatment(s) (24.1%) are all frequently chosen responses (Table 2). The type of treatment received may also guide the timing of information. “In case of hormonal therapy, which affects your entire endocrine system, the professional should provide information before or at the start of the treatment. In addition, advice should be given about how to handle possible side effects such as vaginal dryness” (39-year-old woman). Women may not experience problems with intimacy and sexuality before, during and shortly after the treatment. Therefore, they may have a need for information and advice a longer period after the treatment, i.e. longer than 6 months after treatment. Timing is important when talking about the effects on intimacy and sexuality and to inform patients and partners about ‘what to expect’. “During and immediately after the treatment I did not feel the need to talk about this subject and thought the intimacy would return spontaneously. However, after the treatments the problems became

more clear (low libido, touching the breast was bothersome, early menopause) and more difficult to overcome” (38-year-old woman). Some patients underestimated the impact of breast cancer (treatment) on intimacy and sexuality before treatment and in hindsight they wished they had received the information earlier. “Due to pain and exhaustion I have less sexual desire, which makes me feel guilty to my partner. My partner does not want to talk about it because he feels sorry for me. This has a major impact on our relation” (52-year-old woman). For some women, it even resulted in the feeling that they made the wrong decision regarding the treatment due to the impact on intimacy and sexuality.

Preferred professional

The women who felt a need for information, preferred to receive this information from a nurse/nurse practitioner, their primary doctor or an experienced expert (respectively, 66.4%, 27.9% and 23.1%, Table 3).

In the open-ended question, participants stated that trust was perceived as a main prerequisite for a conversation about intimacy and sexuality. Women stated that doctors need to

Table 3 Preferred professional to receive information about intimacy and sexuality from and preferred communication channel (multiple answers possible)

	<i>n</i> (%)
Preferred health care professional to receive information from (<i>n</i> = 580) ^a	
General practitioner	86 (14.8)
Mammacare nurse/nurse practitioner	385 (66.4)
Primary doctor (surgeon, medical oncologist)	162 (27.9)
Psychologist/social worker/coach	121 (20.9)
Sexologist	120 (20.7)
Patient support group	81 (14.0)
Experienced expert	134 (23.1)
I do not know	63 (10.9)
Preferred communication channel (<i>n</i> = 595)	
Personal conversation with patient	247 (41.5)
Personal conversation with patient and partner	307 (51.6)
Group education for (ex-) patients	48 (8.1)
Group education for (ex-) patients and their partners	59 (9.9)
Telephone contact	16 (2.7)
Website	156 (26.2)
Social media	13 (2.2)
An app	22 (3.7)
Written information (folder or book)	227 (38.2)
I do not know	55 (9.2)

^a87 respondents reported that they did not need information from healthcare professionals. These respondents were not included in the table

be aware of the (possible) effect of breast cancer treatment on the woman herself and their relationship.

Women find it difficult to initiate the conversation themselves about intimacy and sexuality and expect that the professionals initiate communication about this subject. However, women sense that professionals find it difficult to talk about intimacy and sexuality and it is still a taboo. “I found it difficult to initiate the conversation. Once I asked for help, I was referred to the oncology nurse who referred me directly to the gynaecologist. Then I stopped asking for help: two years later it is still a problem” (51-year-old woman). Some women initiated the conversation about this subject, but were disappointed about the reaction of the healthcare professional. “I tried to talk to the medical oncologist about the changes to my body and my relationship. His answer was, you should read about that in [a women’s magazine]” (51-year-old woman).

Preferred information channel

Most patients preferred to receive information about intimacy and sexuality personally, alone or together with their partner (respectively, 41.5% and 51.6%; Table 3). Written information in a folder, a book or online information (websites) were also preferred information channels. Respondents state that it is important to inform both the patient and their partner about the possible changes due to breast cancer. “For me my physical and psychological complaints were clear, however, for my partner it was very important to be informed by a professional and how he/we can cope with these complaints” (60-year-old woman). However, patients wrote that (some) professionals do not take the impact on the relation into account. Including the partner in the process can also benefit the communication between loved ones about intimacy and sexuality.

Not everyone finds an acceptable solution

Some women talk about the changes/problems in intimacy and sexuality with their healthcare professional. However, answers to their questions do not always help to decrease or solve these problems. Women stated they feel they have to choose between survival and sexuality. Some women still experienced problems that were not resolved. “Despite that I willingly gave up part of my sexuality, to improve my chances of survival, the reality is disappointing. I still miss those feelings in my body from before the breast cancer” (58-year-old woman). For other women, the choice between survival and sexuality resulted in a new situation that (in the end) matched their needs. “Intimacy is more essential than sexuality. The sex detached to the background, but our souls found each other” (51-year-old woman).

Discussion

Two-thirds of the respondents reported sexuality problems, which affect both patients and their partners. In only 46% of women, the information received matched their needs. Most women preferred to receive information about the impact of the disease and/or treatment on intimacy and sexuality from a nurse or primary doctor by a conversation with their partner or a personal conversation. Respondents emphasize the importance of appropriate timing of information. However, they differ in their opinion about what this appropriate time is, where most women prefer to receive the information shortly after the treatment started. Women with breast cancer would like to receive information repeatedly with regard to intimacy and sexuality, to be better prepared for the possible physical, psychological and relational changes. However, not everyone finds an acceptable solution.

A previous study showed that the biggest differences in sexuality between women from the general population and breast cancer patients were found in women who were still receiving treatment [19]. These women engaged in less sexual activity (3.0 vs. 4.2, $p < 0.01$), had more sexual stress (2.2 vs. 1.5, $p < 0.01$) and less sexual satisfaction (3.0 vs. 3.7, $p < 0.01$) [19]. For women who finished their treatment, their responses were more in line with women from the general population. These results suggest that sexuality and intimacy go back to normal or patients and partners find a balance in the altered situation [19]. The present study showed that some women found a new situation that (in the end) matched their needs. However, others still experienced problems that were not resolved. In addition, there is a large variety in the preferred timing to discuss the impact on intimacy and sexuality. Hence, there is no ‘one size fits all’ communication model. The changes in the impact of breast cancer in different stages of the treatment and disease underline the importance to repeatedly include intimacy and sexuality in the consultation.

A first step in the communication about intimacy and sexuality is to identify women who need information and guidance to deal with their changes and problems. The present study shows that this step should be repeated at every stage of the disease as this need can change over time. There is little evidence about the aspects of sexuality that should be discussed between patient and professional. A previous study among 1965 breast cancer patients showed that information on physical changes, sexual response, relationship issues, psychological consequences and body image or identity were rated as very important [20]. In the ‘Neo Theoretical Framework of Sexuality’ the impact of cancer covers three domains: sexual functioning, sexual identity and sexual relations [21]. Hence, in the communication about the impact of breast cancer all three domains should be considered.

As shown in the present study, healthcare professional should keep in mind that some women and their partners do not want to discuss sexuality problems with a professional. In addition, patients and partners experienced barriers to talk about problems regarding intimacy and sexuality. Feelings of shame, fear and embarrassment, concerns about how their healthcare professional may react and prioritizing the medical aspects of their sexual problems may play a role [22–25]. On the other hand, healthcare professionals also perceive barriers such as lack of knowledge, lack of training, feeling uncomfortable, sexuality is a private issue and practical problems (e.g. lack of a private environment, lack of services to refer patients and heavy workload resulting in lack of time) [22, 25, 26]. Still, the initiative to discuss intimacy and sexuality should lie with the healthcare professional [8], which is confirmed in the present study. Women who felt a need for information, preferred to receive this information from a nurse/nurse practitioner, their primary doctor or an experienced expert. Although respondents in the present study did not prefer care from sexologist, this care is also available in the oncology setting.

The present study showed that communication could add to a better understanding about ‘what to expect’. However, patients and partners still have to accept the consequence of breast cancer and find a new balance. In this process, the ability to talk about intimacy and sexuality between partners cannot be taken for granted [8]. The healthcare professional can play an important role by involving the partner in the communication and informing both patient and partner. This also supports the communication between partners about intimacy and sexuality. The method of the stepped skills model can guide professionals in the communication about intimacy and sexuality [27]. This is a team approach differentiating between team members who feel confident and comfortable discussing sexual issues (i.e. BLISS member) and team members who have the responsibility to ‘spot’ issues related to intimacy and sexuality (i.e. Spotters) and refer clients to the BLISS members [27].

Several studies showed that professionals should examine assumptions about patients’ communication preferences and information needs [20, 28]. However, no comparisons were made between different cultural backgrounds or common trends (e.g. declining birthrate and late marriage). In addition, communication facilitators were identified, e.g. positive patient–professional relationship, open and collaborative communication [29]. Again, no comparisons were made between different cultural backgrounds or common trends. Future research could focus on differences in preferred communication between countries/cultural backgrounds and common trends in the world (e.g. declining birth-rate and late marriage).

Study limitations and strengths

A number of methodological characteristics of the present study are relevant for interpretation of the results. First, since the study population was recruited via an online exchange forum of Dutch Breast Cancer Patient Association, it is unknown whether the respondents are a representative sample of the Dutch breast cancer patients. The members of the Dutch Breast Cancer Patient Association have on average a higher educational level and a lower age compared to the Dutch breast cancer patients. People with a higher educational level have (on average) a higher health literacy [30]. “Health Literacy has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” [31]. Hence, women with a higher educational level are more likely to seek for information on online platforms and patient organizations (i.e. Dutch Breast Cancer Patient Association). Second, 87 respondents did not answer the question about the preferred healthcare professional to receive information from. This may be explained by the fact that in a previous question they answered that they ‘did not want to receive any information’ or may not want to receive the information from a person but from other sources of information such as leaflet, website. Third, the questionnaire used was not validated. Finally, limited information was collected on the clinical characteristics of the study population. Hence, no subgroup analyses could be performed to get more detailed information about the guidance of women with breast cancer (e.g. difference between women with localized breast cancer vs. metastasized breast cancer). Strengths of the present study are a (relatively) large sample size, more in-depth information about communication on intimacy and sexuality and the opportunity for respondents to share (limited) additional information. Furthermore, combining quantitative with rich qualitative data gave unique insights and perceived values of the patient population [32].

Conclusions

This study shows that intimacy and sexuality should be repeatedly included in consultations, at every stage of the disease but especially shortly after treatment started. Women with breast cancer expect that professionals (preferably nurse or primary doctor) initiate this subject via a personal conversation (alone or with their partner).

Acknowledgements The authors gratefully acknowledge the Dutch Breast Cancer Patient Association (‘Borstkankervereniging Nederland’) for their contribution to the data collection.

Compliance with ethical standards

Conflict of interest The authors declare that there is no conflict of interest.

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