The Breast 43 (2019) 120–122

Contents lists available at ScienceDirect

The Breast

journal homepage: www.elsevier.com/brst

Short communication

Sexuality, a topic that surgeons should discuss with women before risk-reducing mastectomy and breast reconstruction

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ARTICLE INFO

Article history:
Received 28 September 2018
Received in revised form
28 November 2018
Accepted 3 December 2018
Available online 6 December 2018

ABSTRACT

While sexual health is an important aspect of quality of life, sexual issues usually go unaddressed during patient-provider communication. Breast cancer treatments and specifically breast surgery impact women's sexual well-being. However, women do not receive adequate information on this subject. Women who underwent prophylactic mastectomy and breast reconstruction invariably reported that they had underestimated the impact of mastectomy and reconstruction on their sexuality, and expressed a need for information and creating realistic expectations pertaining to sexuality. Therefore, we urge breast surgeons to take the lead in addressing sexuality along with other health-related quality-of-life outcomes during pre-operative consultation.

It is often hard for women to envisage the potential influence prophylactic mastectomy (PM) and breast reconstruction (BR) will have on their quality of life, of which sexual health is a highly important aspect for many [1]. Unfortunately for many, preoperative informed consent, routinely received from their oncological and/or plastic surgeon, does not provide adequate information on this subject. During consultation, surgeons address technical aspects of the various surgical treatments and breast reconstructive methods thoroughly, but often fail to discuss the impact on sexuality and other patient related outcomes.

Several studies have shown that women with breast cancer experience decreased sexual well-being or sexual dysfunction after breast surgery [2,3]. A recent study demonstrated that patients who underwent implant reconstruction had diminished sexual well-being at two years, compared to baseline, while patients who underwent autologous reconstruction had greater sexual well-being at 2 years compared with patients who underwent implant reconstruction [4]. The requirement that women are sufficiently informed of the expected health-related quality-of-life outcomes has been previously emphasized [5–7], however, the need to specifically address sexuality has not been given due emphasis. Relevant information on sexuality prior to surgery helps women making informed decisions and in adapting to their reconstructed body.

So the question arises as to what oncological and plastic surgeons could learn from operated women to improve the quality of information for future surgery candidates? To address this question, we conducted in-depth interviews on experienced sexuality with ten women who previously underwent PM and BR. They also completed the BREAST-Q (Reconstruction module) questionnaire. All women were enrolled at the VU University Medical Center. After providing informed consent, participants were invited for a telephone interview. Semi-structured interviews were held by telephone, according to a standardized protocol. Each interview took approximately 1 h and was conducted by one researcher (RD), who was a trained sexologist. This researcher was the active interviewer, also a second researcher took part as a passive listener. Interviews were recorded and transcribed afterwards. The study was approved by the institutional review board.

We found that experiences with regard to post-operative sexuality varied widely (Table 1), but all women had underestimated the impact of the BR on their sexuality. Although none of these women regretted their decision to obtain PM, most women reported having (had) difficulties with sexuality on several levels; body image, disappointing outcomes with regard to aesthetics and

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https://doi.org/10.1016/j.breast.2018.12.003
0960-9776/

Table 1
Summary of patient interviews.

Patient	Age at interview yrs	FU yrs	BREAST-Q: Sexual well-being	Experience	Expectations	Partner	Care
1	38	6	60	Feels dissociated from breasts, not happy with aesthetic result	For her it was a matter of survival to take this decision, never expected impact	Ex-husband has never touched breasts anymore and left, felt rejected	Looking back, more professional help was needed for both her and her partner
2	48	3	63	Happy with breasts, better than nothing.	Had to adapt to her changed body, was more difficult than expected	Was very happy with the support of her partner	Sexuality is a topic later in the follow-up stage, improvement is needed
3	43	3	72	Never regretted her choices, but had a difficult recovery from the reconstruction	Does not feel different from other women and found a way to accept	Separated from her partner, no understanding from his side	Sexuality should be integrated in recovery process, deserves more attention
4	49	4	49	Has troubles with painful and non-sensitive nipples	Did not expect that the breast reconstruction had a lot of impact	Partner left her in de first year after the reconstruction	Missed someone to talk to about sexuality
5	52	9	52	Missing natural breasts, important role in sexuality	At the moment of decision sexual health was not important	Felt that communication was key to getting through difficulties	Need for information for the partner
6	61	6	47	Heavy process, many psychological issues due to life events	Could live without her breast, but does not regret the reconstruction	Was not able to talk with her partner about it	Though sexuality was not a priority, now she feels the need for help
7	62	12	39	Had a heavy complication and lost her reconstruction	Never will regret reconstruction, but did not expect many reoperations	Husband left her because he was not happy with the reconstruction	Breast are often forgotten in sexuality, had no information
8	41	9	72	Feels the reconstruction does not fit her body	The realization that it will never become real breasts came late	Despite her supportive husband she feels sometimes guilty	The topic sexuality was never mentioned
9	43	9	100	The fear to become sick was more important than the rest	Had realistic expectations, other life events were more important	Supportive partner was very important	More info needed especially about the nipple and sensation.
10	25	4	52	Felt that the reconstruction had a tremendous impact on the body	Expectations did not match result. It took a while to accept new breasts	Had difficulties with finding a new relationship and trust	Important to specify information to age-groups
Median	46	6	56				

sensation, as well as partner relationship issues. With regard to coping with breast surgery and the effects on relationships, much was influenced by support; one woman could share her journey of BRCA diagnosis and the decision-making process with her two sisters, who gave her support during the reconstruction process. Due to the care for a handicapped child, she and her partner had been through a lot. The impaired sexuality had not played a major role for them, as they were mainly grateful still being together. By continuous communication and adaptation, they found a way in their new sexual life. This is in contrast with the case of another woman, where her long-term partner left shortly after the reconstruction process. She did not have a support system and never truly felt secure with her reconstructed breasts. Her impaired sexuality and partner loss played a major role in her life afterwards.

Most women found a way to cope eventually, but they suggested that prior adequate (realistic) information in this regard would improve care and experienced outcomes. Hence, they expressed a need for creating realistic expectations and information pertaining to sexuality. For example, some women specifically missed the sensation in their breast(s) as part of their sexual routine. One participant stated she “had to reinvent herself” and find different arousal strategies; “replacing the feeling in my breasts, other parts of my body became more important for my arousal”. Furthermore, most women felt that the partner should have been more involved and informed about expectations on outcomes and sexuality as well. Some partners were afraid to address the topic, touch the reconstructed breast or disappointed by the outcome. Post-operative guidance also fell short of expectation.

Discussions about sexual health are still uncommon in clinical encounters, despite the sexual dysfunction associated with breast cancer and its treatments. It is known that women experience significant barriers towards speaking out about sexuality [8]. On the other hand, (plastic) surgeons report similar hesitance [9]. In order to close the information gap, breast surgeons should be attentive in taking the lead in informing patients about the impact of PM and BR on sexuality along with other health-related quality-of-life outcomes. Frequently, women and their partners going through the process decision-making, primarily consider cancer risk and survival. As sexuality is shown to be a significant contributor to long-term quality of life amongst survivors, surgeons should counsel these women and couples thoroughly. For example, they can inform on the central role breasts (sensation) can play in sexuality and that breast surgery might affect this negatively. Also, they can inform women on how they may have to redevelop a satisfactory sex life in dialogue with their partner. Instruments such as the BREAST-Q can be used to screen women with an increased risk of developing sexual issues (e.g., those with sexual problems prior to surgery). For those women, and others who require additional support, surgeons can refer to specialist sexologist care during and after the surgical care. With regard to developing a more positive (sexual) self-image after surgery, providing realistic pre-operative expectations is of importance. In order to do so, surgeons should address the possible loss of and changes in sensation, and the possibility of suboptimal aesthetic outcomes. A suggestion to do so is to show “average” instead of unrealistically poor or excellent post-operative aesthetic outcomes when counselling women pre-operatively. Furthermore, more in-depth information is needed about the sexual well-being of women in relation to their breast surgeries.

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