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Changes in Heterosexual Couples' Sexuality During the First Two Years After Breast Cancer Surgery: A Longitudinal Descriptive Study

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Abstract

The study aims to describe couples' changes in sexuality after non-metastatic breast cancer from a longitudinal perspective. Our research question was: how do couples experience the cancer-induced change in sexual frequency and what are the reasons evoked to explain this kind of change over time? Forty heterosexual couples participated in a semi-structured interview three months and two years after surgery. A reflexive thematic analysis was conducted on a specific question about sexuality from a larger interview guide. The results showed that couples follow multiple trajectories regarding sexuality after the onset of oncological treatment. Most couples experienced temporary or more lasting changes, mainly associated with altered body image and pain. Some stopped having sexual activities at the beginning of treatment but resumed sexuality two years later; others were unable to restore sexuality. However, some couples stayed sexually active all along the cancer journey, showing that cessation of any sexual activity is not inevitable. Sexuality represents a significant long-term issue for breast cancer survivors and their partners. Prompt treatment can prevent sexual difficulties from crystallizing, while preserving the individual well-being and the quality of the couple's relationship. Health professionals should be aware of the need to screen early for sexual changes, while reevaluating the couple's situation regularly during care.

Keywords Psycho-oncology · Breast cancer · Sexuality · Couples · Reflexive thematic analysis · Longitudinal design · Switzerland

Introduction

Breast cancer (BC) ranks first in incidence and prevalence among all women's cancers [1], with an annual estimated incidence of 1.67 million new cases worldwide [2]. In terms of mortality (17.7%), BC is the leading cause of death among cancers in women [1]. At the same time, it has one of the best 5-year relative survival rates among cancers: about 80% of women in high-income countries will survive as a result of intense efforts in screening

Extended author information available on the last page of the article

campaigns and advances in medical treatment [3–6]. This implies that a growing number of women live with the aftermath of the disease and its treatment, thus increasing the need to investigate survivors' quality of life in the medium to long term [7].

The illness and the secondary effects of oncological treatment may have a massive impact on women's physical and psychological well-being [8–10]. One dimension that may be particularly affected is sexuality [11–18]. At a physical level, surgery (i.e., lumpectomy or mastectomy; axillary lymph node dissection) can interfere directly with the physical ability to have sexual activity because of pain and discomfort. The pain, often located in the axilla, shoulder, arm, or chest wall, develops shortly after surgery or up to several months afterward; in some cases, it can persist for years [19–25]. In addition, during mastectomy, there is a high risk for injury of the sensory innervation of the breast and nipple areola complex, which may lead to loss of the protective and erogenous sensation in the operated area [21, 26, 27]. Beyond surgery, chemotherapy may induce ovarian failure, leading to premature menopause, vaginal atrophy, vaginal dryness, and decreased libido, which may be the origin of painful and unpleasant sexual activities [28, 29]. Hormonal therapy also decreases women's libido, arousal, and vaginal lubrication, leading to vaginal dryness and dyspareunia [13, 14, 30, 31]. The entire sexual response cycle of the woman may thus be affected by treatment, including sexual desire, arousal, and orgasm [32]. These difficulties lead to a decrease in sexual frequency and satisfaction [13, 16, 33–35].

Oncological treatment also exposes women to marked changes in their physical appearance [36] that may result in body image alteration (i.e., dissatisfaction with appearance, loss of a sense of femininity and attractiveness, and shame) [37–41]. The loss or disfiguration of one or both breasts, considered an essential part of feminine identity, may be particularly distressing and is associated with psychological distress and altered body image [37, 42–44]. Chemotherapy-induced alopecia is also considered by patients to be particularly distressing with respect to their image [44–46]. Weight gain [47–50], tissue damage caused by radiotherapy [51–53], loss of (or the fear of losing) fertility, and more general functional impairment and sensory changes [50, 54, 55] have also been found to affect women's self-perception and appreciation. Studies have shown that the alteration of body image is strongly linked to sexual functioning [56–60].

BC does not only affect the woman but may be understood as a shared stressor affecting the couple as a system [61–63]. Studies have shown that BC can fragilize the couple relationship, inducing tensions, conflicts, communication problems, and lack of social support [64–66], which may in turn negatively impact sexuality [7, 59, 67, 68]. The relational dynamic can therefore influence the sexual one and its evolution; hence the importance of investigating the perspective of both partners. As affected by BC, the sexual behavior of the woman (e.g., refusal or avoidance of sexual contact, hiding her body during sexual activities, a more passive and uninvolved role) [12, 30, 34] and the sexual behavior of her partner (e.g., fear of initiating sexual activities, being afraid to hurt, embarrassment or disgust in touching the operated breast, sexual avoidance) [69–72] both contribute to the couple's sexual dynamics, including its practices, its frequency, and the dissatisfaction of each partner.

According to the literature, sexuality may be significantly affected during treatment. However, many sexual difficulties persist over time, after treatment ends. Longitudinal quantitative studies have shown that even when the overall quality of life of women improved, their sexuality remained problematic and thus represents a significant long-term issue for these women and their partners [73–80]. Qualitative studies, through their focus

on individual experiences, have nevertheless highlighted that sexuality is not affected by BC and its treatment in the same way for everyone, suggesting that there could be multiple trajectories [81, 82]. Unfortunately, existing qualitative studies are generally cross-sectional. This constitutes a possible limitation of the literature because a single measurement point does not allow evaluation of whether the reported difficulties are temporary or established, or if they were already present before BC and thus unrelated to the disease [83].

This study aimed to fill this gap in the literature by describing the couples' experience of changes in sexuality after BC, taking into consideration the different trajectories they can follow over time. To achieve this goal, we have adopted a longitudinal qualitative design. The qualitative approach allowed us to investigate the issue of a decrease in sexual frequency, which constitutes one of the most prevalent sexual changes after BC, and to explore how this change was experienced by couples and the reasons they evoked to explain it. The longitudinal design allowed us to conduct this analysis from a temporal perspective and observe changes' evolution over a 2-year period. Our research question was as follows: *how do couples experience the BC-induced change in sexual frequency and what are the reasons evoked to explain this kind of change over time?*

Materials and Methods

The present study is part of a larger research project on the psychosocial adjustment to breast cancer and its treatments in women and their partners (as individuals and as members of a couple). This project uses mixed methodology to collect data (self-reported questionnaires, semi-structured interviews, and direct observation) [84]. The data presented are from the analyses of the semi-structured interviews exclusively. The original study consists of four measurement time points over a 2-year postsurgical period. Data collection took place between September 2011 and December 2015. In the present study, we focused on the second and last time points, namely, three months after surgery (T1 in the present study) and two years after surgery (T2). This allowed us to analyze two moments that were distant in time and clearly distinct in terms of the cancer care journey: T1 corresponds to the active treatment phase, while T2 corresponds to the rehabilitation phase, when most treatments have ended, except for hormonal therapy.

Participants

During pre-hospital consultation women and their romantic partners were recruited from the Breast Center of the University Hospital of Lausanne, Switzerland. Eligibility criteria for women were as follows: diagnosis of non-metastatic BC, breast surgery required (mastectomy or lumpectomy), age ≥ 18 years, and ability to speak and read French. Eligible partners were individuals aged ≥ 18 years able to speak and read French, who women identified as their boyfriend/girlfriend, husband/wife, or romantic partner. Engagement or marriage was not required, nor was living together.

The original study was proposed to 127 women: 97 (76.4%) agreed to participate and to ask their partner to participate. Sixty-one partners (62.9%) agreed to enter the study. Most participating couples were heterosexual, hence the focus on these couples in the present study. Only the data of women with participating male partners recruited during the pre-

defined time were used. Because of dropouts during the two years of follow-up and missing data (for one or both partners at one or both time points), the final sample size for this study was 40 heterosexual couples.

As shown in Table 1, the participants' mean age was 53.23 years (SD=10.88) for women and 56.34 years (SD=12.29) for partners. The sample's socioeconomic status was mainly (92.5%) middle to upper class (Hollingshead Index of Social Position; [85]). Most of the couples were in a long-term relationship (M=27.28 years, SD=15.94), cohabiting ($n=37$, 92.5%), and married ($n=30$, 75.0%). Regarding cancer diagnosis, most women ($n=35$,

Table 1 Descriptive statistics for sociodemographic and medical data

Characteristic	Full sample ($n=40$)	Long-term-decrease ($n=9$)	Temporary-decrease ($n=16$)
	M (SD, range)	M (SD, range)	M (SD, range)
Age of women, years	53.23 (10.88, 37–75)	51.64 (8.00, 42–64)	49.69 (11.24, 37–70)
Age of partners, years	56.34 (12.29, 28–76)	52.89 (12.01, 41–74)	51.80 (12.06, 28–71)
Relationship duration, years	27.28 (15.94, 2–54)	24.00 (14.34, 3–46)	24.75 (15.94, 4–48)
	n (%)	n (%)	n (%)
Married (yes)	30 (75.0)	6 (15.0)	12 (30.0)
Cohabiting (yes)	37 (92.5)	9 (22.5)	15 (37.5)
Socioeconomic status ^a			
Upper	20 (50.0)	5 (12.5)	9 (22.5)
Middle-upper	9 (22.5)	0 (0.0)	4 (10.0)
Middle	8 (20.0)	3 (7.5)	2 (5.0)
Middle-lower	2 (5.0)	1 (2.5)	1 (2.5)
Lower	1 (2.5)	0 (0.0)	0 (0.0)
Tumor stage			
In situ	5 (12.5)	1 (2.5)	2 (5.0)
Stage I	15 (37.5)	2 (5.0)	4 (10.0)
Stage II	13 (32.5)	3 (7.5)	6 (15.0)
Stage III	7 (17.5)	4 (10.0)	4 (10.0)
Surgical treatment			
Mastectomy	23 (57.5)	5 (12.5)	11 (27.5)
Lumpectomy	17 (42.5)	4 (10.0)	5 (12.5)
Axillary lymph node dissection	14 (35.0)	4 (10.0)	8 (20.0)
Adjuvant treatment			
Chemotherapy at T1 (yes)	4 (10.0)	2 (5.0)	2 (5.0)
Chemotherapy at T2 (yes)	0 (0.0)	0 (0.0)	0 (0.0)
Radiotherapy at T1 (yes)	6 (15.0)	2 (5.0)	2 (5.0)
Radiotherapy at T2 (yes)	0 (0.0)	0 (0.0)	0 (0.0)
Herceptin at T1 (yes)	4 (7.5)	0 (0.0)	4 (10.0)
Herceptin at T2 (yes)	0 (0.0)	0 (0.0)	0 (0.0)
Hormonal therapy at T1 (yes)	22 (55.0)	3 (7.5)	8 (20.0)
Hormonal therapy at T2 (yes)	33 (82.5)	6 (15.0)	12 (30.0)

^a The socioeconomic status (SES) was measured with the weighted cross-product of the level of education (4×1 [university/higher education] to 7 [lower than mandatory education]) and profession (7×1 [executive/manager] to 7 [unqualified employee]) categorized into lower (greater than 59), lower-middle (50 to 59), middle (40 to 49), upper-middle (30 to 49), and upper SES (1 to 29) on the basis of the Hollingshead Index [85]

87.5%) were diagnosed with invasive (vs. in situ) BC: 37.5% ($n=15$) were at stage I, 32.5% ($n=13$) at stage II, and 17.5% ($n=7$) at stage III. Slightly more than half ($n=23$, 57.5%) underwent mastectomy (vs. lumpectomy). Concerning adjuvant treatment, at T1, 10.0% ($n=4$) were receiving chemotherapy, 15.0% ($n=6$) radiotherapy, 7.5% ($n=3$) trastuzumab therapy, and 55.0% ($n=22$) hormonal therapy. At T2, 33 women (82.5%) were still treated with hormonal therapy.

Procedure

During pre-hospital consultation (1–2 weeks before surgery), the referent nurse of the Breast Center systematically proposed taking part in the research to all women who met the inclusion criteria. Women and their partners received documentation on the research and signed an informed consent form. Couples were asked to jointly participate in semi-structured interviews and to individually fill out a sociodemographic questionnaire at each time point. The study was approved by the Ethics Committee of the State of Vaud (Switzerland) in July 2011 (protocol number 228/11).

Questionnaires

Sociodemographic data (i.e., age, socioeconomic status, marital status, length of the relationship, and cohabiting status) were collected with an ad hoc questionnaire. Medical data (i.e., tumor stage, surgical and adjuvant treatments) were obtained from medical records. Sociodemographic and medical data were used exclusively to describe participants' main characteristics.

Semi-Structured Interviews

The interviews with couples (i.e., both partners interviewed concurrently) were conducted by the referent nurse at the hospital during the nursing consultation. Each interview lasted about 45 min and was filmed in its entirety. The interviews were filmed and not simply audio-recorded in order to collect observational data to be used in the larger project, but only audio data were analyzed in the present study. Before the interview, the referent nurse explained to participants that the aim was to speak about their experience of the illness since the diagnosis. She also explained that the interview was organized around a series of questions about the impact of BC on multiple aspects of the couple's life and that these questions served as a starting point for deeper discussion.

In this study, we exclusively focused on a question from a larger interview guide that was specifically related to the impact of the BC on sexuality. The question was as follows: "*Did you experience any significant changes in your sexual life and intimacy after breast cancer?*" The nurse was instructed to ask participants to develop their answers through follow-up questions (e.g., *What makes you say there has been a change/no change? What kind of change have you experienced? Why do you think there has been this change?*). This allowed a collection of nuanced answers that were closer to individual experiences and thus richer than a mere "yes/no" answer. Nevertheless, the mean length of this part of the interview was relatively short: 2.41 min (SD=2.50) at T1 and 2.40 min (SD=2.19) at T2. This was because the original project and the interview guide were not designed for an exclusive

focus on sexuality, and there was not enough time to further develop each question of the interview guide. No other parts of the interview informed the analysis or interpretation of the data concerning sexual life and intimacy. Couples' answers to this question were transcribed verbatim by a master's student in psychology, under the supervision of the first author (SCN).

Interview Analysis

Because the study focused on BC-induced *changes* in sexuality, the first step of the analysis was to identify and select, among the 40 couples, those who reported changes during their interviews. We focused on changes in sexual frequency, which were the issues most often reported in the literature and which had the advantage of being clearly disclosed by couples and thus easier to identify and code. Three coding categories were created for this purpose: *decrease* (i.e., decrease of sexual frequency, including stoppage of any sexual activities, compared with before BC); *resume* (i.e., sexual improvement at T2 compared with T1; this included resumption of sexual activities following complete cessation or increased frequency of sexual activities following reduction), and *no change* (i.e., no significant change in sexual activities following BC). For each couple, we coded whether there was a decrease in sexual frequency, a resumption, or a lack of change at both T1 and T2. To achieve greater accuracy for descriptive purposes, we introduced an additional distinction between couples who were already sexually inactive before BC and couples who were sexually active before the disease. This information was also extracted from the participants' answers to the interview question. By combining the assigned codes at both time points, we were able to group couples into different patterns of evolution.

Given our research aim, only the data of couples who reported changes in their sexuality after BC were analyzed in order to describe how changes were experienced and the reasons evoked to explain the changes over time. Concerning couples who reported no changes, we mention only their number and percentage in the [Results](#) section without describing or discussing these specific patterns in more detail.

The transcripts were analyzed by the second author (TM), a researcher who had training in qualitative research methodology, by using NVivo software (NVivo 12.6.1). The coder followed the reflexive thematic analysis guidelines for coding and developing themes [86, 87]. This method was conceived to identify and organize patterns of meaning in a data set. The first step consisted in immersion in the data to become familiar with the content of interviews through repeated readings of the transcripts. After this careful reading, the second step consisted in coding the data, working through the text in order to identify meaning units, and labeling them with a code that captures the meaning identified. The coder tried not to let the coding be driven by ideas, categories, and definitions from previous research to allow for a more inductive, data-driven approach. The codes were thus "grounded in the data" [88]; no predefined codes based on existent studies or a specific theoretical framework were used. In a third step, the coder reviewed all the codes, looking for connections between them and paying attention to any patterns in the data. This allowed grouping of codes into a smaller number of higher-level codes referred to as categories. Categories were subsequently regrouped to create overarching themes, defined as "patterns of shared meaning, united by a central concept or idea" [87].

To answer our research question (i.e., *how do couples experience the BC-induced change in sexual frequency and what are the reasons evoked to explain this kind of change over time?*) and offer the most accurate description possible, we simultaneously considered the following aspects in the presentation of results: the couples' different patterns of evolution, the two measurement time points (allowing a temporal perspective), and the discourse of couples (summarized in themes and illustrated by verbatim quotes).

Results

Four Patterns of Evolution

The patterns we created were as follows (see Table 2): (1) *long-term-decrease* couples (i.e., couples reporting having decreased or stopped sexual activities at both T1 and T2, compared with the pretreatment period; $n=9$, 22.5%), (2) *temporary-decrease* couples (i.e., couples who reduced or stopped sexual activities at T1, but reported an improvement at T2; $n=16$, 40.0%), (3) *active-stable* couples (i.e., sexually active couples who reported no significant changes at both T1 and T2; $n=5$, 12.5%), (4) *inactive-before-BC* couples (i.e., couples who were already sexually inactive before BC and who reported no significant changes at both T1 and T2; $n=10$, 25.0%). Only two of these patterns (1 and 2) were characterized by change and were therefore considered for the qualitative analysis. These 25 couples reported a decrease in sexual frequency or a stoppage in sexual activity at T1 and 9 were still in this situation at T2 (*long-term-decrease* pattern).

Concerning couples assigned to a *long-term-decrease* pattern, four of nine completely stopped having sexual activities at T1, while five experienced a decreased frequency. At T2, five couples reported a stoppage (one more than at T1) and four still experienced a decreased frequency compared with before BC. Concerning the *temporary-decrease* pattern, five couples of 16 had completely stopped sexual activity at T1, while 11 experienced a decreased frequency. All 16 couples of this pattern reported an improvement in their sexuality in terms of frequency at T2 (i.e., resumption of sexual activities for couples who had previously stopped, or increased frequency for the others). Globally, nine couples of 25 had completely stopped having sexual activities at T1, and less than half of them ($n=4$) managed to resume sexuality within T2. Improvement was more prevalent among couples who had simply decreased frequency: 11 couples of 16 reported improved sexual frequency at T2.

Experiences and Perceived Reasons for Change

Through the analysis of the 25 couples reporting a sexual change after BC, we generated seven themes, namely: (1) sexuality was not a priority, (2) painful sexual contact, (3) altered body image, (4) relationship implications in decreasing or stopping sexuality, (5) resuming

Table 2 The four patterns of evolution between T1 and T2 ($n=40$ couples)

	T1	T2	<i>n</i>	%
1. Long-term-decrease	Decrease	Decrease	9	22.5
2. Temporary-decrease	Decrease	Resume	16	40.0
3. Active-stable	No change	No change	5	12.5
4. Inactive-before-BC	No change	No change	10	25.0

but not resetting, (6) acceptance of the “new” body, (7) relationship implications in resuming sexuality. These themes have been integrated in the two sections that follow (*Couples’ experiences of stopping or decreasing sexuality* and *Couples’ experiences of resuming sexuality after decreasing or stopping*) to describe the experience of couples reporting changes in sexuality in terms of stopping, decreasing, or resuming sexuality over time.

Couples’ Experiences of Stopping or Decreasing Sexuality

In this section, we report the results of the analysis concerning all couples reporting a decrease or stoppage at T1 (i.e., couples belonging to both the *long-term-decrease* and the *temporary-decrease* patterns) and couples who continued to experience a decrease or stoppage at T2 (*long-term-decrease* pattern).

Sexuality was not a Priority Three months after surgery, there are couples having experienced a change in sexual frequency (i.e., a decrease or stoppage) who stated that their only priority at that moment was the fight against cancer. As one woman explained: “On the sexual level, no, everything stopped since the diagnosis announcement was made. We had the impression that... well, it was really secondary... it was really secondary” (W6, T1). Referring to the treatment period, another woman disclosed: “I wasn’t often well, was I? So, it’s not fun, you can’t think about, er... having hanky-panky” (W1, T1). Sexuality was thus not a primary concern. At this time, partners were mainly described by the women (or they described themselves) as sensitive and understanding. They were focused on the woman’s survival and on how to best support her. Partners did not complain about the regression of their sexual lives and rarely asked for sexual intercourse: “Sex... It’s... it’s not vital. The main thing is to have someone who is fit next to you” (P1, T1). BC, and its possible life-or-death implications, took the main place, making sexuality a secondary activity.

Couples who still reported a decrease or stoppage in sexuality two years later (*long-term-decrease* pattern) no longer mentioned that sexuality was not a priority in explaining their situation. This suggests that the importance or the place of sexuality in the couple had presumably changed again and that the origins of decreased or stopped sexuality were to be searched for elsewhere.

Painful Sexual Contact Pain, more specifically pain from touching the operated breast and/or pain during penetration (because of vaginal dryness), was evoked by couples as a reason to decrease or stop sexuality at T1. There are partners who were reluctant to touch the woman’s breast because they feared hurting her or because they knew she feared being touched. As one partner explained: “I mean... I try to surround my wife as best as I can and then uh... avoid certain areas that are still very, very sensitive, that’s for sure, yeah, yeah” (P7, T1). It was the same with sexual intercourse with penetration: “We won’t be able to force it and then it will hurt her...” (P1, T1). Another partner talked about a “retreat phenomenon” from sexuality to avoid pain (P3, T1). Fear of pain can lead to a sense of constraint and loss of freedom, which can seem in contradiction with an ideal of free, spontaneous, and instinctual sexuality: “And then, uh... for me, it’s not ideal... because you can’t... you’re not free. I don’t think we’re free to do what we can” (W10, T1).

Quite surprisingly, at T2, relatively few couples still reported painful intercourse due to hormone therapy-induced vaginal dryness; for these couples, the woman’s dyspareunia was the origin of low sexual frequency. No couples still mentioned the partner’s fear of touching the woman’s breast, probably because the postoperative pain was mostly gone.

Altered Body Image Beyond pain, one factor that appeared to play a central role in couples' sexual changes and difficulties at both T1 and T2 was altered body image. Among the many possible bodily changes, breast loss or disfigurement due to surgery, as well as chemotherapy-induced alopecia, seem to be of particular importance in affecting the women's sense of femininity and attractiveness. Concerning hair loss, one woman stated: "I've been well... scalped, eh!" (W1, T1). This harsh term was used sarcastically by the woman as if to mask the distress that alopecia has caused her. Another woman stated: "It's... it's weird though, isn't it, to be a woman... uh without uh... breast" (W2, T2). The loss of breast has led some women to question the true essence of being a woman and the role of breast as a symbol (of femininity, sexuality, maternity). The changes experienced were such that women may no longer recognize themselves in their changed body, leading to a loss of self-confidence: "There was... a... a loss of self-confidence... that is, my image has changed, I'm not the same person in the same body" (W3, T2).

Like pain, body image difficulties seem to be more salient at T1. At that time, treatments were still ongoing, and changes were recent and still shocking, requiring time to be integrated or accepted. One woman reported, for example, that she could no longer even look at or touch her operated breast: "It's, it's incredible. I never thought that one day I would be afraid of my body of... of not wanting to touch it [...]. But I can't. Even I can't touch myself" (W4, T1). Women may have felt the need to take some distance from their own body, to avoid it on multiple sensory levels (touch, sight) to protect themselves from too difficult a confrontation.

The discomfort that the women felt toward their body had repercussions for how to have intimate and sexual contact with their partner. Some women refused to show themselves naked, or even to be touched. One woman disclosed: "When he tries to touch me, I... he usually touches me on my belly and everything, I... I can't do it. I can't do it..." (W4, T1). The questioning of one's femininity and attractiveness has led some women to feel guilty toward their partners, as if they were "forcing" them to touch and look at this new altered version of themselves. One partner reported about his wife: "She would get undressed and then say to me 'I'm sorry... I don't feel like a woman anymore' [...]. She had the feeling that she no longer knew how to give what a woman could or should give" (P2, T1).

Unfortunately, the woman's anxiety about her appearance may have been unintentionally strengthened by her partner avoiding touching the operated area. Not being touched, over time, can lead the woman to feel that her partner is no longer sexually attracted to her or even disgusted by her altered body. A vicious cycle can ensue and inhibit the rise of sexual desire. Some partners described their avoidance behavior as spontaneous and unpremeditated, and they could not say what drove them. As one partner explained: "I didn't know why, if it was because I was embarrassed, if it was because I didn't dare touch her, if it was because I was afraid of hurting her, if I was afraid of my reaction" (P3, T1). This partner mentioned fear of how he might react (i.e., what he might feel and/or how his body might act). The doubt he seems to express about his ability to eroticize the woman's altered body led him to avoid physical contact.

Two years later, there are couples still experiencing a stoppage or decrease in sexuality who continued to perceive body image as a barrier to improving their sexual life. The women in these couples still felt disfigured and mutilated, or, as one woman said, like they were "a half portion" (W5, T2), meaning that BC and its treatments had deprived her of a

significant part of herself. In these cases, intimate and sexual contact with the partner may therefore be limited or completely avoided.

Relationship Implications in Decreasing or Stopping Sexuality It is important to highlight that couples who reported a stoppage of sexual activity or a decrease in sexual frequency at T1 and/or T2 did not experience a deterioration in their relationship. On the contrary, they reported that their bond had even strengthened at T1. As one partner said: “I would say for the... the physical side uh, the mechanical side... is fading uh... plays less of a role... while the relationship taken as a whole is growing in intensity” (P9, T1). This was also true for couples who still experienced a stoppage or decrease at T2. In these couples, stopping or decreasing sexuality seemed to be their strategy for adapting their sexuality according to their current situation and needs. Putting aside the more physical and genital dimension of their relationship was thus not perceived as a threat to their intimacy, which was instead “nurtured” and enriched by other aspects (tenderness, cuddling, mutual support, etc.). Some couples searched for temporary “alternatives” to sexuality, especially by replacing it with hugs and increased tenderness and affection: “We always kept our cuddle time, our time together. So that [sexuality], I mean uh... it’s because I wasn’t well that I didn’t need it and he didn’t either... But these [cuddle times], we kept” (W6, T1). These couples seemed to have good communication skills, which allowed them to share their feelings and make choices that respected each other’s needs. In these couples, the partners were generally described as very sensitive and understanding by the women: “I find that... he’s very respectful... of... of all that. So, it’s kind of... I didn’t have to say it, I’m a princess” (W3, T1). Under these conditions, the couple relationship was preserved. However, changes in sexuality may be accompanied at T1 by a fragilization of the bond, making it more difficult to communicate constructively to find sustainable and respectful solutions. At T2, a stoppage or decrease may still be accompanied by relationship difficulties: “I think that there is also perhaps, um... that on my side there is a kind of fatigue from... from not reinvesting in our relationship” (P4, T2). The fatigue this partner mentioned suggests a certain passivity and fatalism that leads each partner to maintain the status quo even if it leads to an unsatisfying relationship.

Couples’ Experiences of Resuming Sexuality after Decreasing or Stopping

In this section, we report the results of the analysis concerning the 16 *temporary-decrease* couples at T2 (i.e., the time point when they reported experiencing improved sexuality).

Resuming but not Resetting Although most couples managed to resume sexuality within two years after surgery, this was generally not as before the disease. As one partner explained: “It’s true that I probably don’t see her the same way anymore and she... [looking at his wife] maybe you don’t behave the same way anymore, so, uh... so, necessarily, the... the relationship changes and uh... and uh... the approach... in the context of a sexual relationship, also changes...” (P8, T2). The experience of cancer can change the way both partners behave as well as their respective roles in the couple: due to the illness, their roles were defined as the “ill” women (the fragile victim) and the partner “carer” (protector). This shift in roles can persist over time, altering how partners perceive each other and how they interact, including in the sexual sphere. Despite an improvement compared with T1, sexual activities may still be less frequent than before BC. Changes thus persisted, as did certain difficulties, requiring

both partners to adjust: “Afterwards, we start again... But we start again differently, that’s for sure. [...] we adapt ourselves. Yeah, we adapt. Yeah, we adapt” (W7, T2). Sexual intercourse may still be painful for the woman due to hormonal therapy-induced vaginal dryness, which made sexuality less enjoyable and thus less frequent than before BC: “So, little by little, yeah, we’re starting to get back to, uh... the intimate life we had before. Yeah. But well, there are always the consequences...” (W6, T2). The changes were not exclusively about frequency, however; practices may have been “adapted” (P8, T2) and new ways found to live and enjoy sexuality together. These changes were perceived as positive because they allowed couples to regain intimacy and improve their sexuality.

Acceptance of the “New” Body At T2, women no longer evoked breast ablation or other physical alterations as having a main role in their sexual lives. This might suggest that they had somehow managed to adapt to their bodily changes and accepted living with them: “I feel comfortable like this. Even though my body is not like before” (W8, T2). At the same time, the fact that this issue was not evoked at T2 could mean that women simply no longer spontaneously talked about it with their partners (or maybe did not dare to). Partners may in some cases wonder whether there has really been an acceptance: “Sometimes, I wonder if she doesn’t have difficulties to accept her body... But uh... that’s another debate...” (P9, T2). The women who still explicitly evoked body image-related difficulties said that these difficulties had been mitigated over time, becoming less debilitating for their sexual life. Nevertheless, these difficulties remain present and important enough to be mentioned.

Relationship Implications in Resuming Sexuality Partners continued to be generally described as sensitive regarding the woman’s health and well-being. Nevertheless, some misunderstandings could arise. As the treatment side effects such as vaginal dryness or decreased sexual desire were mostly invisible, it would sometimes be difficult for the partner to understand why the woman did not want to have sex as often as they did before BC. Discouraged, partners may have stopped any attempt to initiate sexual intercourse, believing it to be useless: “I say to her ‘yeah, but uh... every other time you say “no, I’m not too good and all that,” so we say well, never mind, uh...” (P1, T2). Another partner reported: “It was more like uh... yeah, fear of disturbing, fear of choosing... the wrong time...” (P9, T2). In these cases, men waited for the woman to take the initiative, thus avoiding being rejected. This avoidance of initiative on the part of a partner who was previously initiator, could lead the women to believe that he no longer desires her and to feel rejected.

At T2, some partners seemed to focus again on their own sexual needs (which had been partially or totally repressed until that moment) and asked the woman (more or less subtly) to resume sexuality. Sexuality seemed thus to be no longer secondary and had regained an important place in their life. Depending on the couple, the request to resume sexuality was received differently by the women. When couples were able to openly communicate about this topic, they managed to find compromises and mutually acceptable solutions. The topic could even be discussed with humor in some cases: “We don’t ask ourselves which was better... Christmas or making love? Well, I’m thinking a bit, and... Meh, Christmas because it’s more frequent” (P5, T2). Even if the solution was not always ideal for both partners (e.g., too low frequency), this allowed them to regain an intimate and sexual contact that was sometimes avoided or feared for a long time.

However, women may not have been ready yet, but felt pressure to respond positively to their partner’s request because of feelings of guilt. Some women admitted having forced themselves to have sexual intercourse to satisfy their partner. As one woman explained, “if

my partner wants to have sex, I'm not going to refuse... because I know it's a need..." (W9, T2). The fact that men had to give up these needs for a long time "because of them" leads some women to prioritize their partners' sexual well-being, even if this means enduring painful and/or pleasureless sexual intercourse: "I think that she's not ready... for... for sex. But let's face it, she has made an effort from time to time" (P6, T2). As much as this "effort" may be appreciated by the partner, the risk is for the woman to reinforce a vicious circle where sexual activities are not motivated by sexual desire and where sexuality is lived as a painful experience. This may in the long run reduce sexual satisfaction within the couple and lead to a subsequent decrease or avoidance of sexual activities.

Discussion

This longitudinal descriptive study provides a better understanding of how heterosexual couples' sexuality changes three months and two years after starting BC treatments.

A major objective of this study was to understand the reasons behind the decrease or cessation of sexual activities three months after surgery. At this point in the treatment process, sexuality was not a priority for the couples. They were fighting cancer and appeared to be too preoccupied with the progression of the disease (e.g., fear that the woman would die). Sexual needs may have been put aside by partners. However, for some, sexual life may have been maintained by adapting sexual practices (e.g., sex without penetration), or replaced with tenderness and affection. The reduction or cessation of sexual activities thus represents an adaptive process widely used by couples. Moreover, body image alteration seems to be the main reason for this decrease. It is important to remember that this is the postoperative period, when body changes are recent. In our sample, many women developed avoidance behaviors during intimate moments (e.g., not showing themselves naked, or refusing to let their partner touch the operated breast), illustrating discomfort with their own bodies. Our findings support previous studies [37–39, 41, 89] that highlighted the harmful impact of BC and its treatments on body image (e.g., dissatisfaction with appearance, loss of a sense of femininity and attractiveness, and feelings of shame). In addition, couples reported that the reason that they had fewer sexual activities or stopped all forms of sexuality was that they experienced pain during sex (e.g., in the chest, during vaginal penetration). Indeed, BC treatments are known to increase vaginal dryness and to decrease sexual desire, making sexual activities less enjoyable or even painful [13, 14, 28–31]. It is therefore advisable to offer medical (e.g., lubricants and moisturizers) and psychological help if needed [90] so that sexuality can remain as pleasurable as possible for each partner. Alteration of body image and the presence of pain seemed to create a vicious circle in which sexuality gradually became synonymous with pain and was increasingly avoided. Sexuality was often experienced in a context of unpleasant emotions (e.g., guilt, fear of having sex or of doing harm) in which avoidance behaviors toward sexual activities progressively increased in both women (e.g., fear of pain, lack of desire, guilt) and men (e.g., no longer feel desired, avoid penetration). For example, when the partner avoided touching the woman's body, she may have experienced this as rejection and confirmation that her body is no longer attractive, reinforcing the vicious cycle.

Another objective of this study was to observe the evolution of the couples' sexuality two years after surgery. Women seemed to be more accepting of their body changes induced

by treatment. In fact, they no longer reported alterations in their body image. At this stage, BC may have brought partners closer and improved their couple life. Intimacy is built on two components: self-disclosure and appropriate partner response [91]. It is possible, therefore, that the BC experience promoted, in some couples, better communication about their intimate and sexual needs, leading to feeling a sense of closeness and support from their partner.

However, although most couples increased the frequency of sexual activities by two years after surgery (*temporary-decrease* pattern), some difficulties remained. Previous research suggests that BC treatments decrease couples' sexual frequency and satisfaction [13, 16, 33–35]. Women experience the side effects of hormone therapy (decreased sexual desire and arousal, as well as vaginal dryness) that are often invisible (e.g., fatigue, loss of desire) and sometimes difficult to understand for the partner. Although sexuality appeared to be, once again, a priority for the couples in our study, the resumption of sexual activities emerged at the request of the partner who felt that he put his sexual needs aside for a long time. Women had indeed little motivation to resume sexuality, and some still reported pain during sexual activity. Our study confirms previous research that reports women may feel guilt and pressure for not meeting their partner's sexual expectations and will sometimes force themselves to have painful, non-pleasurable sex [34, 64, 92, 93]. According to Gilbert and colleagues [7], sexual problems can become one of the most problematic aspects of survivors' lives. Our study indicates that sexual pain plays an important role in reducing or ceasing sexual activities at the beginning of treatment and can also interfere with couples' sexuality over the long term. Moreover, sexual pain is the sexual dysfunction that most impairs couples' sexuality after BC. It should therefore be assessed and managed at the beginning of the treatment process.

Couples who stopped all forms of sexuality completely at treatment onset did not follow the same trajectory. Their chances of remaining sexually inactive after two years was more than one in two. This can be explained by the fact that women still had an altered body image, and intimacy and sexual relations were still avoided. According to Tay and colleagues [94], when sexuality stops, other forms of intimacy and affection (e.g., touching and physical contact) may gradually diminish or disappear altogether, contributing to a failure in resuming sexuality. Health care professionals should therefore consider couples that stop all forms of sexuality early in treatment as a group at risk of being unable to resume sexuality in the long term.

Our longitudinal study offers clinical insights into how and when to address couples' sexuality after BC. According to Del Pup et al. [95], sexual dysfunction is widely recognized as a side effect of BC treatments but remains rarely assessed and treated. Health professionals and patients are reluctant to address sexuality due to embarrassment, lack of time, respect of privacy, and lack of knowledge about human sexual functioning [96, 97]. The results of the current study suggest that primary prevention techniques should be applied from the onset of BC treatments. This includes offering an open dialogue with patients about sexual health and sexual dysfunction resulting from cancer and its treatment, as recommended by the American Society of Clinical Oncology guidelines [97]. This prevention phase would allow couples to realize that sexuality is not taboo and that they can talk openly about it or seek professional help if needed. It also allows professionals to assess sexual dysfunction and identify couples who stop all forms of sexuality at the beginning of treatment. It would be ideal to assess couples' sexual functioning through routine examination [95]. After two

years, couples presented a greater desire to return to a satisfying sex life. Professionals can more easily offer sexological interventions if sexual difficulties persist. Our study highlights the importance of assessing the sexuality of both partners after BC and confirms Carroll and colleagues' [43] literature review results. According to these authors, the most effective intervention for sexual dysfunction after BC integrates several elements: couple sex therapy (e.g., pain management), partner support and communication skills, and body image. Addressing only one of these elements will not improve sexual functioning.

To the best of our knowledge, this is the first longitudinal qualitative study to describe couples' sexuality changes after BC. Strengths of our study include the qualitative description of sexuality at two distinct points in the care pathway (i.e., active treatment phase and rehabilitation phase) and the inclusion of 40 couples (women and their partners), which allowed us to identify different patterns of evolution in the sexuality of couples facing BC. At the same time, the study has some methodological limitations, as the absence of specific data on pre-diagnostic sexual functioning and the composition of the sample, including that it consisted exclusively of heterosexual couples who were mostly married and had long-standing relationships. Further longitudinal studies should examine the evolution of sexuality after BC in other kinds of couples (e.g., unmarried, non-hetero) and extend the focus beyond frequency to include other dimensions of sexuality such as desire, pleasure, satisfaction, and communication. This would deepen knowledge on their multiple trajectories.

We recommend that sexuality be discussed with couples as early as possible during treatment. Couples should be offered the opportunity to talk about sexual practices throughout the course of treatment, as specific sexual difficulties may persist over time.

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Data Availability The datasets generated during and/or analyzed during the current study are not available because the Data Use Agreement does not allow the release of the data.

Declarations

Ethical Approval This study was performed in line with the principles of the Declaration of Helsinki. The Ethics Committee of the State of Vaud (Switzerland) approved the study protocol in July 2011 (protocol number 228/11).

Consent to Participate All participants consent to having their data published in a journal article.

Consent for Publication Not applicable.

Competing Interests The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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