



Sexual quality of life evaluation after treatment among women with breast cancer under 35 years old

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Abstract

Purpose To qualify the quality of patients sexual lives after treatment among women with breast cancer under 35 years old and compare results to the literature.

Methods Sexual quality of life was measured for 84 women aged 20 to 35 years old at diagnosis, with two validated quality of sexual life questionnaires, Brief Index of Sexual Functioning for Women (BISF-W) and Female Sexual Function Index (FSFI), at least six months after breast cancer diagnosis. Two other questionnaires were used to allow us to understand other aspects of their life before cancer and to monitor quality of sexual life during treatment.

Results Forty-three women responded to the questionnaire. The questionnaires demonstrated that more than half of them had problems with their sexuality. The mean total score was 28.08/75 for BISF-W and 25.1 for FSFI (under the cutoff score 26.55). The domain analysis showed an association between the absence of chemotherapy and scores in regard to sexual health. Only 7% had sexual disturbance detected but 49% of the patients wished to have it.

Conclusion Sexual dysfunction in breast cancer survivors is real, has several factors, and cannot be evaluated based only on the organic side effects induced by cancer treatment. Better monitoring and screening seems necessary in order to optimize the quality of sexual life after surviving breast cancer.

Keywords Sexuality · Sexual health · Breast cancer · BISF-W · FSFI

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Background

Breast cancer is the most common cancer in women and has the highest incidence in the world with 1,671,149 new cases in 2012, one cancer on four among women in the world. Eleven percent of these cancers are diagnosed under 40 years old [1, 2]. Overall survival increased and the improvement of quality of life including sexual health becomes a major issue. Five-year survival is actually about 86% for 15–44 year-olds [3].

Sexual health is a pertinent and valid parameter for sexual quality of life evaluation, even more so with young women, during childbearing age. Sexual disturbances are reported by 9 to 43% of the general population [4].

Psychological and physical side effects of cancer treatment are well known. Surgery can lead to pain, wound-healing disturbances, lymphedema, adhesions and retractions, and sensitive disturbances. Radiotherapy can lead to fibrosis, pain, atrophy, and telangiectasia. Among systemic treatments, alterations depend on the therapy type (chemotherapy, monoclonal antibodies, hormonal therapy), dose, and scheme of administration. Side effects are premature menopause (amenorrhea, hot flashes, weight gain, loss of libido, vaginal dryness), alopecia, and fatigue [4, 5]. Psychological effects are lower self-esteem, body image disorders, declined interest in sex, relationship alteration, and a deterioration of social and professional life, up to depression syndrome [6]. There are also age-specific problems: desire to have children and infertility risk, child-rearing already in place. Some studies have demonstrated that women aged 45 years and under were more vulnerable to negative disease effects with a most important alteration of quality of life [7–9].

The cutoff age of 35 years was chosen in order to have a young population. Literature considers this population most likely at risk of psychosocial complications [9, 10]. There is a risk of infertility and a poorer prognosis because of tumor aggressivity [10]. Most studies focus on patients older than 50 years because of higher cases of breast cancer and the coexistence of menopause [11]. It demonstrates lower psychological complications, which affects success and treatment choice [10, 12].

Sexual health is a state of physical, emotional, mental, and social well-being associated with sexuality. It does not only consist of the absence of disease, dysfunction, or infirmity. It is often poorly treated in medical consultation. For Usher et al., 85% of patients report a negative impact of the cancer and the treatment on sexual life, and among the 68% of patients who wished for information about it, only 41% received it [13]. One-third of couples wished for simple care such as a prescription and another third specialized care [14, 15]. There are various reasons: priority settings, disinterest, lack of knowledge or know how, network of professionals unknown, difficult to speak about, and taboo. In order to help practitioners, questionnaires are available, even if there is actually no gold standard [8, 9].

The main purpose of our work is to assess the sexual health of women under 35 years after treatment for breast cancer and compare results to the literature.

Patients and methods

It is a quantitative, cross-sectional, and descriptive study performed on women treated in an integrated center of oncology as “institut de cancérologie de l’Ouest Paul Papin” (ICO) in Angers, or in a clinical insitute specialized in oncology as “Centre Jean Bernard” (CJB) in Le Mans.

Patients (18 to 35 year-old woman at diagnosis) were selected between 2008 and 2012, the period of 5 years allowed a higher number of patients and the end of hormonal therapy for some of them. The inclusion period was finished in 2012 in order to avoid the impact of the cancer announcement and to allow surgery and chemotherapy to have finished for at least 6 months. It was demonstrated that sexual quality of life is lower when less than 1 year has elapsed since the date of diagnosis [12, 16, 17]. The exclusion criteria were distant metastasis, death, and protective measures concerning incapable adults. These criteria were used to select our population and collect medical informations, prior to sending questionnaires.

Four questionnaires were sent to patients. Their answers were mailed to each center with anonymously prepaid postage. They were prompted by a call in the absence of a response. Evaluation of sexual quality of life in the previous 4 weeks was performed by two self-reported questionnaires: BISF-W (Brief Index of Sexual Functioning for Women) and FSFI (Female Sexual Function Index).

The 22 questions of BISF-W evaluate seven parts of sexuality: desire (D1), sexual arousal (D2), frequency (D3), receptivity (D4), orgasm (D5), relationship satisfaction (D6), and problems affecting sexual function (D7). A composite score can now be generated by adding domains one through six and subtracting the seventh domain. The seventh domain is subtracted so that a higher score will reflect a greater degree of sexual function. The range of composite scores is from –16 to +75. There is no screening value but the lower the score is, the poorer the sexual function.

The 19 questions of FSFI evaluate six sexuality items: desire, sexual arousal, vaginal lubrication, orgasm, satisfaction, and pain. Each question is scored from 0 (or 1) to 5. The scoring algorithm sums items on each domain/subscale and then scales the sums so that each subscale has a maximum score of 6. The FSFI total score is the sum of the 6 domain/subscale scores and has a maximum score of 36. Higher scores indicate better functioning. A screening value of 26.55 has been validated to diagnosis sexual disturbance.

The two other questionnaires were homemade and are not validated in the literature. The third one was created in order to obtain an idea of their sexual satisfaction before breast cancer

diagnosis (Appendix B). The last one was created to know how questionnaire they prefer and to see if they have a follow up of their sexuality since cancer treatment (Appendix A).

The main outcome was the result of composite scores for the first two questionnaires. Data from BISF-W and FSFI were expressed as mean \pm standard deviation and data from population as percentage. Categorical data were analyzed with χ^2 test (or Fisher exact test). Means were compared with Wilcoxon or Kruskal–Wallis test except for comparison with literature, Student *t* test. All statistical tests were performed at the two-sided 0.05 level of significance. Statistical analysis was performed using Epi Info®.

Results

All the population characteristics are summarized in Table 1 and Fig. 1. Women who answered to questionnaires were 43 (51.19%). Their characteristic comparison between nonresponding patients has not shown a significant difference. Average age was 32.1 years. Eight patients were diagnosed in 2008, four in 2009, nine in 2010, ten in 2011, and twelve in

2012. There were as many patients with a mastectomy as lumpectomy, but more axillary node dissection because half of them had at least one axillary node ($p = 0.83$). Radiotherapy adverse events were not evaluated because all patients had received it.

The analysis of prognosis factor on sexuality is summarized in Table 1, and has not shown significant difference on FSFI and BISF-W score. Surgery has no impact on scores, whether it is for treatment ($p = 0.65$ and $p = 0.77$), for axillary node ($p = 0.63$ and $p = 1$), or reconstruction ($p = 0.4$ and $p = 0.09$). The use of adjuvant therapy has not shown a significant difference on scores, with chemotherapy ($p = 0.22$ and $p = 0.32$), hormonotherapy ($p = 0.72$ and $p = 0.58$), and trastuzumab ($p = 0.8$ and $p = 0.65$). Women who were nulliparous have same scores as that of women with children ($p = 0.31$ and $p = 0.42$).

Results of BISF-W are summarized on Table 2. Among the 43 patients, 37 (86%) had a partner and 32 (74%) had sexual activity over the past 4 weeks. All patients were heterosexual like declared on question 2 of BISF-W questionnaire. The mean total score was 28.08 ± 15.87 .

Results of FSFI are summarized on Table 2. Three patients were not included because of issuing no response to questions 15 and 16. The average total score was 25.14 ± 8.09 , less than

Table 1 Population characteristics for all included patients ($n = 84$), nonanswering women ($n = 41$), and responding patients ($n = 43$) with their composite score. All included patients corresponding to the sum of patients responding to included study criteria. The first “p” column is a comparison of population characteristics, the second is the comparison of

FSFI scores ($n = 40$) according to these prognosis factors, and the third the same comparison with BISF-W scores ($n = 43$). BISF-W and FSFI scores are presented as Mean (SD), *p* values are computed with Wilcoxon test or Kruskal–Wallis test. NS = No significant

	All included patients $n = 84$ (100%)	Nonanswering women $n = 41$ (48.81%)	Responding patients $n = 43$ (51.19%)	p	FSFI score ($n = 40$)	p	BISF-W score ($n = 43$)	p
Age				NS		NS		NS
20–24	2 (34)	0	2 (4.7)		26.1		21.22 (21.8)	
25–29	16 (16)	9 (22)	7 (16.3)		23.6 (9.8)		26.92 (13.8)	
30–35	66 (78.6)	32 (78)	34 (79)		25.1 (8.1)		28.73 (16)	
Surgery				NS		NS		NS
Lumpectomy	36 (42.9)	16 (39)	20 (46.5)		25 (9.4)	NS	26.86 (17)	NS
Mastectomy	48 (57.1)	25 (61)	23 (53.5)		25.22 (7)		29.15 (12.1)	
Sentinel node	22 (26.2)	10 (24.4)	12 (27.9)	NS	24.7 (10.4)	NS	27.7 (16.9)	NS
Dredging	62 (73.8)	31 (75.6)	31 (72)		25.3 (7.1)		28.23 (15.8)	
No reconstruction	45 (53.6)	19 (46.3)	26 (60.5)	NS	26 (8)	NS	30.82 (16.2)	NS
Immediate	24 (28.6)	14 (34.2)	10 (23.3)		21.1 (10.2)		18.58 (14.8)	
Deferred	15 (17.9)	8 (19.5)	7 (16.3)		26.7 (4.9)		31.49 (12.1)	
Chemotherapy				NS		NS		NS
Absence	8 (9.5)	5 (12.2)	4 (9.3)		19.5 (11.4)		20.81 (17.6)	
Neoadjuvant	43 (51.2)	18 (43.9)	25 (58.1)		24.9 (7.8)		26.91 (15.5)	
Adjuvant	33 (39.3)	18 (43.9)	14 (32.6)		27.4 (7.1)		32.25 (16.2)	
Hormonotherapy				NS		NS		NS
Absence	33 (39.3)	17 (41.5)	17 (39.6)		24.6 (9.3)		29.77 (17.8)	
Presence	51 (60.7)	24 (58.5)	26 (60.5)		25.5 (7.4)		26.98 (14.8)	
Trastuzumab				NS		NS		NS
Absence	64 (76.2)	30 (73.2)	34 (79)		25.4 (8.1)		27.5 (16.1)	
Trastuzumab	20 (23.8)	11 (26.8)	9 (20.9)		24.3 (8.6)		30.29 (15.6)	
Pregnancy				NS		NS		NS
Nulliparous	22 (26.8)	9 (23)	12 (27.9)		27.9 (5.4)		30.91 (14.3)	
Child	60 (73.2)	30 (76.9)	31 (72.1)		24.1 (8.7)		26.99 (16.5)	

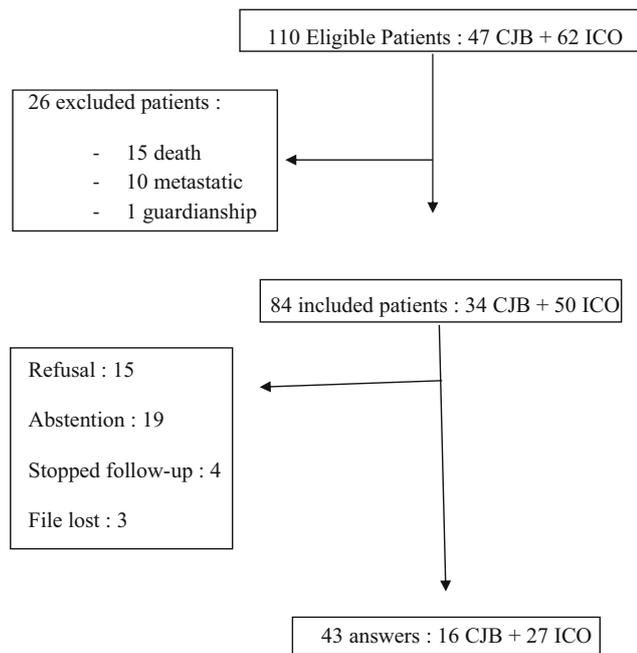


Fig. 1 Flowchart of the study

the screening value of 26.55. This value was not reached for 55% of patients.

Comparison of BISF-W's and FSFI's scores with a control group of literature is presented in Table 2. The population of Rosen's study was women with and without sexual dysfunction

diagnosed with DSM-IV criteria (respectively $n = 307$ and $n = 261$). Mean age was 36.2, aged to 18 to 74 years. We selected the FSFI score of 244 women in their control group. The population of Caremel's study was women aged 25 to 70 years, with a mean age of 44 years, who visit our general practitioner, with a sexuality thank like normal ($n = 100$). We selected the BISF-W score of women who were not menopausal ($n = 73$). Comparison of BISF-W's composite score 33.45 ± 12.33 and control group in Caremel's study showed a significant difference ($p = 0.0296$). This sexual function score was significantly worse for the index group than the control group.

The detection of sexual disturbance was not researched in thirty-nine patients (91%) but nineteen (49%) of them wished to have had it.

The last questionnaire demonstrated that 95% of patients are attached and 76% of them to the same partner as before breast cancer. Fourteen percent of women had an unsatisfactory sexual quality of life, 65% satisfactory, and 21% excellent, before diagnosis; neither relate nor sexual activity or dissatisfaction.

Discussion

Using the four questionnaires, we qualify the quality of patients' sexual life after treatment among women with breast cancer under 35 years.

Table 2 Summary of FSFI's and BISF-W's scores, and comparison with control group based on literature. Scores are presented as mean (SD), p -values are computed using Student t test. Caremel's study population is composed of pre-menopausal women control group. NS = no significant

Domains	Theoretical maximal range	Range	Studied sample	Control group	p -value
FSFI			N = 40	Rosen's study population [18] N = 244	
Desire	1.2 / 6	1.2 / 6	3.82 (1.23)	4.28 (1.12)	NS
Arousal	0 / 6	0 / 6	4.01 (1.66)	5.08 (1.11)	NS
Lubrication	0 / 6	0 / 6	4.55 (1.76)	4.45 (1.14)	NS
Orgasm	0 / 6	0 / 6	3.95 (1.84)	5.05 (1.30)	NS
Satisfaction	0.8 / 6	0.8 / 6	4.31 (1.6)	4.04 (1.19)	NS
Pain	0 / 6	0 / 6	4.49 (2.02)	5.51 (1.29)	NS
Composite score	2 / 36	3.2 / 34.2	25.14 (8.09)	30.75 (4.80)	NS
Score < 26.55			22 (55%)		
BISF-W			N = 43	Carmel's Study population [19] N = 73	
D1 (desire)	0 / 12	0 / 10.14	4.23 (2.8)	4.62 (2.35)	NS
D2 (arousal)	0 / 12	0 / 11.25	5.4 (3.39)	6.67 (2.42)	0.0167
D3 (frequency of sexual activity)	0 / 12	0 / 8.75	3.13 (2.06)	3.7 (2.01)	0.0745
D4 (receptiveness)	0 / 15	0 / 15	7.88 (4.35)	8.69 (3.04)	NS
D5 (pleasure)	0 / 12	0 / 9.25	4.07 (2.9)	5.54 (2.18)	0.0024
D6 (relational satisfaction)	0 / 12	0 / 12	7.65 (2.98)	8.45 (2.56)	0.0722
D7 (problems affecting sexuality)	0 / 16	1 / 9.23	4.96 (2.09)	4.22 (2.22)	NS
Score	-16 / +75	-0.8 / 55.57	28.08 (15.87)	33.45 (12.33)	0.0296

Results showed sexual disturbance with lower scores, 28.1 for BISF-W and 25.1 for FSFI, compared to general population. Half of patients wished to have a detection of sexual disturbance while 7% received it.

Questionnaires

BISF-W and FSFI are two quality of sexual life questionnaires which are validated, reliable, and standardized [16, 19–23].

The strengths of BISF-W are a multifaceted approach of sexuality, a French validation and possibility of use for sexually inactive women or homosexual women. The weak point is an approach too detailed and intimate which decreases the response level. This questionnaire is not neutral regarding the sexual preference of women: if one activity is not practiced, the results will be decreased when there is no sexual trouble. Response time is long (20 min) and the lack of limit value reduces its interest.

The strengths of FSFI are a wider use and reproducibility of results, a limit value at 26.55. It was demonstrated that a value under 5 in the first part (desire) has a good positive predictive value [20]. The disadvantages are the impossibility to use it for women who have sex with women or women who have no sexual activity over the past 4 weeks, an organic approach of sexuality, predominant on vaginal lubrication, so without a psychological analysis.

BISF-W was preferred by patients like answered in the third questionnaires (Appendix A). While FSFI is more simple to use, BISF-W is more appropriate for these kind of patients, whose psychological side effects are overriding. It evaluates psychological aspects with questions about the impact of family or social problems, the importance of sexuality for the patient, the self-esteem, and what they think about partner satisfaction. In the two cases, the retrospective nature of the questions could distort results. Patients explained that the analysis in the previous 4 weeks is less representing their sexuality.

Results of BISF-W and FSFI questionnaires

The mean total score of the BISF-W was 28.08. Domains most altered were the frequency of sexual activity and orgasm. Domains least affected were receptivity and relationship satisfaction. This score was small in comparison to the literature. In Caramel's study [12], using the BISF-W with 25 to 70 years old women, the mean was 32.18 [17] and 33.45 [12.33] for pre-menopausal control group, with a significant difference. The comparison with this last group, which showed a significant difference, gained an idea of the general population score, all the more there is no screening value for the BISF-W.

With the FSFI questionnaire, the mean total score was 25.14, less than 26.55. Domains most altered were desire and orgasm. This composite score is also lower than the control population in literature: 30.5 ± 5.3 for Rosen et al. and

30.75 ± 4.8 for Wiegel et al. [24]. The Baser's study [25], realized among patients with gynecological cancer without breast, showed an altered composite score at 24.75 ± 6.75 , as did our population.

Desire and capacity to achieve orgasm are multi-component domains with an important psychological part, notably difficult to relax and enjoy the moment [18]. Half of women treated for breast cancer described a decrease in sexual desire [23]. Those domains are also closely connected because reduction of one impacts the other negatively. Relationship is preserved for 92% of cases [6], which explains higher results in relationship satisfaction domain and receptivity.

We used Rosen's study and Caremel's study to compare their control group to our population [12, 24]. This two studies had a control group with common population characteristics like our population, especially Caremel's study, with the selection of not menopausal women. This comparison permitted to see that there is a significant difference between the two BISF-W's scores, even if they are not paired, of 5 points. This suggests that they had a poorer sexuality after cancer treatment. The difference with FSFI's score was not significant even if there is a difference of 5 points too. Maybe the menopause induced by treatment is responsible of the same sexual perturbations like menopausal women included in this control group.

Even if this score is under the screening value, it is not plummeted. Their sexuality is altered but medical help could certainly ameliorate their sexual quality of life, and increase their score in order to approach general population score.

Bias

The data collection methods, at home, did not allow us to verify if patients had filled in the questionnaire alone, even if they said they had. The lack of transfer and anti-transfer bias was the advantage. In function of doctor's sex and doctor–patient relationship, answers could be unintentionally different, to not disappoint one's doctor or impress him, or because they are afraid to modify the cancer treatment. Sexuality could be seen as a taboo or too personal to be approached in a medical visit, so it is easier sometimes to be alone to answer questions, using an anonymous method [16]. Even more, questionnaires assess quality of life after cancer with a retrospective mode, which is a limitation of the reality of the answer.

Another bias was the lack of recent sexual activity. Our choice was to exclude the three patients who had not answered at least one question. Some studies had excluded patients who had not answered eight questions or more [21]. Others excluded women who had not had sex during the last 4 weeks [11]. In Rosen's study, allowed FSFI validation in the English version [25], the presence of women who had no sex in the last 4 weeks was questioned because of a significant decrease of total score, but it is not demonstrated. Even if they had no sexual relation, they also had an activity which could be

evaluated, like sexual fantasy, desire, and masturbation; but relationship and sexual relation was not evaluated so BISF-W is more useful in this indication.

Maybe, the sexual health concerns cannot be entirely contributed to cancer. Patients can have other problems that can influence sexual health, in addition or not with cancer disturbances. The complementary answers in the question 5 of the second questionnaire, reported that cancer was the cause of sexual disturbance for 50% of them, relationship conflict for 26%, partner health for 15%, and lack of intimacy for 26%. More causes were reported for 24% of them, in addition with cancer treatment, like professional difficulties, fatigue, difficult to relax, sadness.

It could be interesting to touch partner's sexual satisfaction to how these confounding factors have an impact on their sexuality.

Response level was 51%, less than literature studies with the same data collection, expanding 65 to 90%, but which stabilizes around 50% after 5 years of treatment [16, 22, 24]. It could be explained by the fact that the two questionnaires were sent in the same time period, which increases the time to respond and repetitive questions. Among the 84 patients included, there were 15 refusals. Patients were contacted by phone, when they had not spontaneously answered. All women who were contacted by call, were open to research on sexuality, and had confided their unhappiness on this, even if they did not participate in the study. There is a real need to communicate on it. The intrusive nature of questions could deter women from responding. We could ask if patients who participate in the study are the ones who had less difficulty speaking of sexuality, inducing a selection bias.

Follow-up

Half of women wished to have a sexuality follow-up during cancer treatment. It proves that this subject must be approached during medical visits, and it is currently not realized. Quality of sexual life evaluation must be integrated in the care pathway [15].

The aftercare of sexuality could be realized by health professionals. The use of these questionnaires is not necessary for regular follow-up. There is only a complementary tool for the physician. Health professionals can only ask patients how their sexuality is during medical visit, in order to give an advice, or a medicine, or refer to a specialist. Questionnaire could be used when sexual disturbances are not clear or difficult to evaluate.

Conclusion

Sexual quality of life of breast cancer patients is globally altered by a multifactorial mechanism. The two validated questionnaires

used in this study, BISF-W and FSFI, demonstrated it. Even if scores are lower compared to general population, the difference could be deleted or reduced by a good medical approach.

A real offset exists between women asking for a sexuality follow-up and medical inclusion. This study confirms to practitioners how approaching sexuality is inseparable of global care. The place of consultation, by a general practitioner, gynecologist, or oncologist, to discuss sexual health and address sexual trouble is essential. The questionnaires can only be a complementary tool to a physician's examination.

Author's contribution Anaïse Blouet participated in conducting the study, collecting the data for the study, and in writing the manuscript.

Yoann Pointreau and Marie Zinger participated in the writing of the manuscript.

Valérie Thepot Seegers participated in the statistical analysis.

Olivier Capitain participated in revising the manuscript.

Hugues Bourgeois participated in revising the manuscript and in the construction of the study.

Sebastien Landry participated in revising the manuscript and in the construction of the study.

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Compliance with ethical standards

This study obtained the agreement of the ethical committee from Angers University Hospital. All the authors are consent to publication. Informed consent was obtained from all individual participants included in the study. The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflicts of interest The authors declare that they have no conflicts of interest.

Abbreviations FSFI, Female Sexual Function Index; BISF-W, Brief Index of Sexual Functioning for Women; ICO, Institut de cancérologie de l'OUEST; CJB, Centre Jean Bernard

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