

Breast Cancer Patients' Experience and Wishes Regarding Communication on Sexual Health - The BEROSE Study

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Research Article

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Keywords: Communication, Sexual Health, Breast Cancer, Survey

Posted Date: April 26th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-427074/v1>

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Abstract

Purpose: Although sexual health (SH) is a major concern for many patients with breast cancer (BC), only few of them receive adequate information on this topic throughout their care. BEROSE is a single-center pilot cross-sectional observational study, which aimed at evaluating communication on SH between women with BC and their health-care providers.

Methods: From June 12th to July 31th, 2020, a survey was distributed to patients consulting at Breast Cancer Unit of Gustave Roussy Cancer Center. The primary endpoint was the rate of women reporting to have received information on SH from health professionals throughout active treatment administration or BC follow-up.

Results: Of 348 surveys collected, 318 were completely filled and included in the analysis. Sixty-one percent of women were older than 50 years and 65% had a localized BC. The majority (63%) was receiving hormone-therapy (37%) or chemotherapy (26%). Overall, 65% reported that they had not received any information about SH throughout their care, while 69% felt it would have been important to discuss sexual issues. Most of women expected professionals to bring up the topic, preferably oncologists or gynecologists, during face-to-face consultations. Concerning satisfaction on SH, 83% reported of being satisfied or very satisfied before BC diagnosis, and only 30% at the time of our survey.

Conclusion: Most of women treated or followed-up for BC feel that they lack of information regarding SH-related issues. The impact of BC diagnosis and treatment on SH should be discussed with all women from the first visit and then regularly readdressed.

Introduction

Breast cancer (BC) represents the most common cancer in women in the world [1]. Thanks to improved screening programs and systemic and locoregional treatments, the mortality from BC in Western countries is steadily decreasing. Patients with metastatic BC are living longer, by virtue of more effective systemic therapies [2, 3]. Thus, it has been estimated that two million women in Europe have currently a BC history [4]. Maintaining a long-term quality of life is therefore a major health concern among women that are being treated for early and advanced BC [5].

In this context, several studies have evaluated the impact of BC on women's sexual health (SH), with 34 to 85% of women who reported sexual problems during and / or after BC treatment [6–8]. Multiple factors and treatment side effects may directly or indirectly affect SH. Body image modification induced by local and systemic therapies, along with weight gain and fertility impairment associated to chemotherapy and endocrine therapy can severely undermine patient's self-confidence [9, 10], especially in young women [11, 12]. In addition, fatigue, pain, vaginal dryness, decreased desire and hot flushes that tend to persist long time after treatment termination can hinder the recovery of sexual well-being [13–15]. Finally, the psycho-social burden deriving from the diagnosis of BC and treatment side effects, including fear of changes, fear of cancer recurrence and death, changes in social

and work position [16, 17] and changes in the couple dynamics [18–21] are major obstacles to a normal SH [22–24].

So far, the issue of sexuality in women with BC is often under-addressed [22, 25, 26] although prior studies showed that 68% of women with BC experience sexual difficulties and 60% sought to receive information on BC-related sexual changes, regardless the stage of the disease [27] even in advanced cancer or palliative care [28, 29]. Women often do not raise the question as the decline in the quality of sexual life is perceived as a “price to pay” [30] or they do not feel comfortable to discuss the subject with their healthcare providers and would prefer the professionals to bring up the subject [31, 32]. On the other side, for healthcare professionals, SH is a difficult topic to discuss due to lack of adequate training [33], lack of time [34, 35], or embarrassment [36].

Health-care providers thus play a key role in providing timely information on the sexual consequences of BC diagnosis and treatment and advising women and their partners on the possible solutions. Nevertheless, few studies evaluated patients’ perceptions regarding communication on SH by health care providers, at different time points of treatment delivery and follow-up. We therefore conducted this cross-sectional study, among women with all stage BC from a single large comprehensive cancer center, with the aims of determining the rate of women who received SH information from health professionals and describing the characteristics of such communication as well as identifying patient’s satisfaction with the information received.

Methods

DESIGN AND SETTING

BEROSE study (Breast cancEr patients’ expeRience with cOmmunication on Sexual hEalth) is a cross-sectional observational pilot study carried out at Gustave Roussy Cancer Center (GRCC), a comprehensive cancer center located in a large urban area (Villejuif, France).

PARTICIPANTS

From June 12th to July 31th, 2020, women ≥ 18 years old, with any stage breast cancer, who had an in-person visit or a teleconsultation in the Breast Cancer Unit at GRCC and receiving treatment or in follow-up, were offered to participate to the survey. Women were considered ineligible if they had severe cognitive or psychiatric illness or if they were unable to read and/or write in French language.

PROCEDURES

Participants who came to GRCC for an in-person visit could choose between a paper or digital survey. The latter was administered using SurveyMonkey link (<http://www.SurveyMonkey.com>), accessible through a QRcode. Women who had teleconsultations received an email containing the link and the corresponding QRcode. Women who had multiple consultations during the study period were invited to reply the survey

Loading [MathJax]/jax/output/CommonHTML/jax.js y anonymized and no personal information was collected

from participants. The study was approved by the Institutional Review Board (IRB) on April 28th, 2020 and was internally validated by the data protection officer as required, regarding compliance to the EU General Data Protection Rules. No written informed consent was required from participants.

QUESTIONNAIRE

No validated questionnaires exist that evaluate communication between patients and health-care professionals about SH in women with BC; therefore, we created an *ad hoc* questionnaire, building on published studies about SH. The questionnaire was reviewed and validated by a panel of diverse healthcare professionals at GRCC including medical oncologists, nurses, gynecologists and psychologists with long-term experience BC and by patient advocacy groups. The final version was reviewed by the research team, tested on a small sample of volunteer patients, and modified according to their comments. The final questionnaire is available in the supplementary appendix and comprises 30 questions divided into 3 main sections: general information (10 questions) including age range, education, family composition, menopausal status, comorbidities, and co-medications; information on BC and treatments (5 questions) such as early or metastatic BC, treatments received and ongoing; and questions on women's SH (15 questions) including: current satisfaction with sexual life compared to sexual life before BC diagnosis, communication on SH with health-care professionals after the diagnosis of BC, nature of communication, who initiated the communication and when, patients' preferences, and barriers on communication about SH.

PRIMARY AND SECONDARY OUTCOMES

The primary outcome was the rate of women who received information from health professionals about SH at any time during their BC care, from diagnosis to follow-up. The secondary outcomes were (1) to describe the main characteristics of such communication on SH, (2) to assess the perceived impact of breast cancer/its treatments on sexual satisfaction, and (3) to explore factors associated to women's satisfaction with SH and to communication on SH after BC diagnosis.

STATISTICAL ANALYSIS

Descriptive statistics were used to describe patients' characteristics (age range, education, family composition, menopausal status, comorbidities and co-medications), BC characteristics (stage and type of treatments), satisfaction with SH and communication on SH.

Primary outcome was computed as the proportion of women who received at least one communication on SH after the diagnosis of BC.

Continuous variables were expressed using medians and ranges. Categorical variables were summarized using absolute count and percentages.

Current sexual satisfaction was compared retrospectively to sexual satisfaction diagnosis and / or before treatment using a McNemar test.

We also explored the association between the single following variables: women's age range, tumour stage and ongoing treatment and the items: (1) women reported satisfaction with sexuality before BC diagnosis and at time of survey (2) perceived importance of addressing sexuality during BC follow-up.

Associations were tested using Kendall's correlation tests for ordinal variables, Cochran-Armitage trend tests, or Chi-square or Fisher's exact tests when appropriate.

As these latter analyses were exploratory, p-values were not corrected for test multiplicity so they should be interpreted with caution.

All analyses were performed using R (version 4.0.3) and the *tverse* packages [37, 38] with a significance level of 5% for 2-sided tests.

Results

A total of 580 women were given the paper questionnaire, while 62 were invited to fill the questionnaire in digital form after their teleconsultation; 329/580 (57%) and 19/62 (31%) women filled the paper and online questionnaire respectively. After removing incomplete questionnaires (n = 25, 7.5%) and overt refusals to participate in the study (n = 5, 1.5%), 318 questionnaires were evaluable for our analysis (94% in paper version and 6% in digital version; Fig. 1).

PARTICIPANT CHARACTERISTICS

Main participant characteristics are summarized in Table 1. Sixty-one percent of women were older than 50 (n = 194). Almost 80% were married/partnered (n = 253) and 86% (n = 275) had at least one child. The majority (n = 166, 52.2%) had a higher than college education level. Forty percent (n = 128) of women were postmenopausal before their diagnosis of BC and treatment initiation, 79% at the time of the survey. Sixty-five percent (n = 206) of women declared to have a localized BC. The majority were currently receiving chemotherapy or hormone therapy (n = 83, 26% and n = 118, 37% respectively, Table 2). The median time since BC diagnosis was 3 years [range, 1–7].

Table 1
General clinical and socio-characteristics of the participants

Participant characteristics		N = 318	%
Age	< 30 years	4	1.3
	30–39 years	34	10.7
	40–49 years	86	27.0
	50–59 years	118	37.1
	60–69 years	61	19.2
	> 70 years	15	4.7
Marital status	Partnered/Married	253	79.6
	<i>Median couple duration (years, [IQR])</i>	<i>21 [14–30]</i>	
	Single	65	20.4
Child(ren)	Yes	275	86.5
	No	43	13.5
Education level	Primary or High school	57	17.9
	College	85	26.7
	Higher than College	166	52.2
	Unknown	10	3.1
Menopausal status at BC diagnosis	Post-menopausal	128	40.2
	Pre menopausal	190	59.8
Current menopausal status	Post-menopausal	250	78.6
	Amenorrhea for less than 1 year	34	10.7
	Regular menstrual cycles	34	10.7
Other chronic pathology	Yes	72	22.6
	No	246	77.4
Other chronic treatment(s)	Yes	54	17.0
	No	264	83.0
BC = breast cancer			

Table 2
Cancer stage and treatment characteristics

Tumor and treatment characteristics		N = 318	%
Time from BC diagnosis	<i>Median (years, [IQR])</i>	3 [1–7]	17.9
	< 1 year	57	49.7
	1–5 years	158	32.4
	> 5 years	103	
BC stage	Localized	206	64.8
	Metastatic	94	29.6
	Unknown	18	5.7
Current treatment	Before starting any treatment	2	0.6
	After surgery and before any other treatment	7	2.2
	During chemotherapy	83	26.1
	During radiotherapy	12	3.8
	During hormone therapy	118	37.1
	Other	23	7.2
	After any treatment	67	21.0
	Unknown	6	1.9
Prior treatments	Surgery:	279	87.7
	Lumpectomy	123	38.7
	Mastectomy with immediate or delayed reconstruction	106	33.3
	Mastectomy without reconstruction	50	15.7
	Chemotherapy	269	84.6
	Radiotherapy	227	71.4
	Hormone therapy	187	58.8
	Other	53	16.7
	Unknown	1	0.3

BC = breast cancer

Overall, 65% (n = 207) of women reported that they did not have any conversation with any health care provider regarding their SH (Fig. 2 and supplementary Table 1S). Fourteen percent of those who had had a discussion with a health care professional (n = 45/318) had brought up the topic on their own.

Two-thirds of women (n = 218, 69%) reported that they considered important to discuss sexual issues during the visits planned for their BC treatment, and 31% (n = 100) expected the professionals to bring up the conversation on the impact of BC diagnosis and treatment on SH. When sexual consequences were discussed, it was mainly in terms of adverse effects that treatments could engender on sexuality: the health-care provider informed of their possible occurrence (n = 32) or asked if such adverse effects had present (n = 39). Sexual well-being was directly addressed in only 4.1% (n = 13) of cases (Table 1S).

When asked what was the best time for such communication, 45% (n = 145) of women estimated that this was “along the whole care pathway”. The majority also would have liked to be able to discuss their sexual concerns in the presence of their partner (n = 277, 87%). Participants reported that their preferred physician for such discussion was their oncologist (n = 161, 51%), their gynecologist (n = 129, 41%) or a sex therapist (n = 81, 26%). Finally, the majority of women wished to discuss sexual consequences of BC in a face-to-face consultation (n = 218; 69%) or, to receive information through a specific leaflet or website (n = 117, 37% and 49, 15% respectively).

SEXUAL HEALTH AFTER BREAST CANCER DIAGNOSIS

Women were questioned *a posteriori* on their satisfaction with their sexuality before the diagnosis and / or treatment of BC and then at the time of the survey (Supplementary Table 1). The majority of women reported to be satisfied with their sexuality before their BC diagnosis (166, 52%; Fig. 3) or even very satisfied (98, 31%). At the time of questionnaire collection, satisfaction with sexual life had significantly decreased ($p < 0.0001$) and only 30% of women stated to be satisfied or very satisfied with their sexuality (76, 24% and 18, 6% respectively). Two-thirds of women (n = 213, 67%) perceived a negative impact of cancer and its treatments on their sexuality (supplementary Table 1), mainly due to increased vaginal dryness (n = 134, 42%), decreased desire (n = 121, 38%) and a change in body image (n = 86, 26%). For 28% (n = 90) of women, sexuality was not a topic worthy of concern at the time of the survey. Interestingly, almost a fifth of them reported a positive impact of cancer on their sexuality (n = 60, 19%), mostly in virtue of an improved communication with their partner (26, 8%).

EXPLORATORY FACTORS ASSOCIATED TO SEXUAL HEALTH SATISFACTION AND COMMUNICATION ON SEXUAL HEALTH

We also evaluated the association between age range, tumor stage and ongoing treatment (especially chemotherapy and endocrine therapy versus other treatments) with the prior BC diagnosis and current satisfaction with sexuality and the communication on SH.

Age was not associated with satisfaction with sexuality before BC ($p = 0.22$) or at the time of survey ($p = 0.49$). Communication on SH was of less importance to women with older age ($p = 0.03$), however, 64% of

the patients in the oldest group (> 70 years) still considered this topic important (supplementary Fig. 1S).

Tumor stage was significantly associated with satisfaction with current sexuality, a lower satisfaction being more frequent in patients with metastatic tumors ($p = 0.005$; Fig. 2S).

Finally, ongoing treatment was not significantly associated with current satisfaction with sexuality ($p = 0.16$; Fig. 3S).

Discussion

Although SH is an important dimension of quality of life and BC diagnosis and therapies are associated with a high risk of developing transient or permanent sexual disturbs, very few women obtain information or have access to an appropriate counseling focused on sexual issues after BC diagnosis.

Our study confirms the lack of communication between patients and health-care professionals on SH in women with BC. Our results are consistent with the data in the literature with nearly 4 out of 5 women not having received information from health professionals [26, 39].

Furthermore, we found a significant deterioration in women's self-rated satisfaction with their quality of sexual life compared to pre-diagnosis [25]. It is also interesting to note that almost one in five women was not satisfied with her SH before BC was diagnosed. These figures are consistent with those carried out by *Lammerink et al* in 2017 in the Dutch general population in 521 sexually active and healthy women, of whom more than a quarter had sexual dysfunction [40].

Women preferred to be provided with information on SH throughout their treatment plan, starting at diagnosis, as recommended by the American Society of Clinical Oncology (ASCO, [41]) and by national societies, such as the French Association of Supportive Oncological Care (AFSOS, [24]). Participation of the partner to the discussion on SH was essential for most of participants [20]. Despite the lack of training of oncologists in SH, they were the favorite interlocutors for women, certainly due to the relationship of trust that can develop throughout the whole BC care pathway [39]. Thus, oncologists are expected to initiate the discussion [25, 32] on the impact of BC on SH, preferably during face-to-face consultations, with a clear and inclusive language that put the women and their partners at ease to raise specific questions on this topic.

We were able to draw some interesting data from our exploratory analyses. Indeed, as already shown in other studies [33], age did not affect sexual satisfaction, although SH seemed to be a little less essential to discuss for older women.

As expected, metastatic status appeared to be more associated with poorer quality of sexual life [28], but SH issues was as much important to discuss as for women with early BC.

In contrast to previous studies [10, 13], current oncological treatment at the time of the survey (such as

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appear to be associated with decreased sexual satisfaction.

However, these results are only exploratory and need to be confirmed by additional studies.

Better management of SH has the potential to increase adherence to treatments [42, 43], to reduce certain symptoms such as anxiety or depression associated to BC care and to improve communication within the couple and in the family [18, 44–46], with a substantial positive effect on the daily well-being.

The first step is to inform about the consequences of the disease and its treatments on SH and provide advices on the possible remedies for the woman and the couple. Regardless of age [47], disease curability [32] and phase of treatment [26], early and regular support on SH must be offered to all women facing BC diagnosis and treatments, in full respect of woman's preferences, cultural diversities and feelings [48].

To this purpose, health professionals should receive adequate training to discuss sexual disorders with their patients and to provide them appropriate counseling [49].

Our study has some limitations. First, it was conducted in a single large cancer center to which are frequently referred patients with more complex or advanced BC or at younger age, who may require a highly specialized multidisciplinary approach, so it is likely that the survey participants are not sufficiently representative of the overall population with BC. Indeed, being the majority of women in our sample highly educated, it is likely that many of them may have voluntarily addressed to a highly specialized center. However, in our study, we used wide inclusion and exclusion criteria to assess patient-care provider communication on SH in a heterogeneous population with different BC stages and treatments and coming from various geographic areas, so making our results more generalizable. Furthermore, the age structure of our sample is fairly representative of that of women with BC in France [50]. Second, because our study was based on the response to a questionnaire that was collected only once over the BC care pathway, we were not able to assess the longitudinal evolution of sexual quality of life over treatment and follow-up and we cannot exclude a recall bias when women were asked to compare their current SH with the one before BC diagnosis. Third, we cannot use a validated questionnaire, as to our knowledge a questionnaire validated to evaluate communication on SH in patients with cancer does not exist. However, our questionnaire was created after a large literature review, piloted and reviewed by a multidisciplinary team. Finally, we were not able to precisely estimate the rate of refusal to participate as multiple channels were used to address women with BC. Indeed, we expected a higher recruitment. It was not reached probably for multiple reasons, such as the heavy emotional context faced by patients consulting for BC, the content of the survey as well as the major changes in outpatient visits due to the Covid-19 pandemic. This lower recruitment makes BEROSE study not powered for identifying factors associated to SH and likelihood of communicating on this topic.

In conclusion, SH, although recognized as central component of quality of life remains in general and in particular in the oncological field, a theme that is rarely mentioned. Our study clearly underlined that all patients, regardless of age, BC stages and ongoing treatment, are concerned about the possible impact of BC treatments on sexual function and are interested in maintaining a good sexual quality of life [24, 41].

Declarations

Funding (information that explains whether and by whom the research was supported): not applicable.

Conflicts of interest/Competing interests (include appropriate disclosures):

B. Pistilli: consulting fees from Puma Biotechnology, Novartis, Myriad Genetics, Pierre Fabre ; travel from Novartis, AstraZeneca, MSD Oncology, Pfizer ; Research fundings from Daiichi, Puma Biotechnology, Novartis, Merus, Pfizer, AstraZeneca. I. Vaz Luis: Honoraria from Amgen, Pfizer, Novartis. A. Di Meglio: Honoraria from ThermoFisher Scientific. The other co-authors declare no conflict of interest.

Availability of data and material (data transparency): all data generated and analyzed during this study are available from the corresponding author upon reasonable request.

Code availability (software application or custom code): not applicable.

Authors' contributions (optional: please review the submission guidelines from the journal whether statements are mandatory): not applicable.

Ethics approval (include appropriate approvals or waivers): this study has been approved on April 28, 2020 by a French Ethics Committee.

Consent to participate (include appropriate statements): by completing the questionnaire, participants gave their consent.

Consent for publication (include appropriate statements): not available.

Acknowledgements: Thanks to R. Le Grand and AL. Gerard for their precious help in the realization of this study.

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Figures

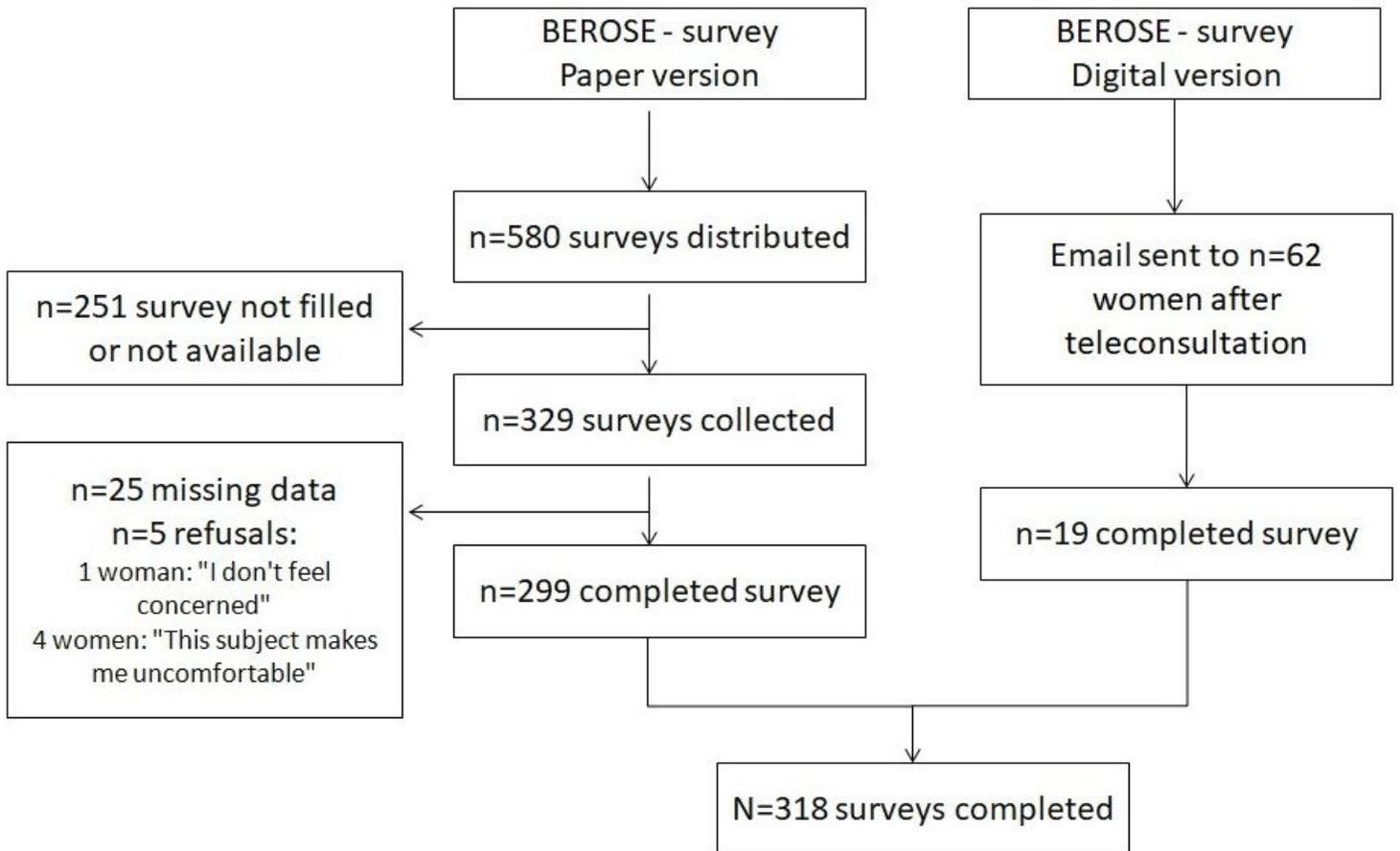


Figure 1

Consort diagram

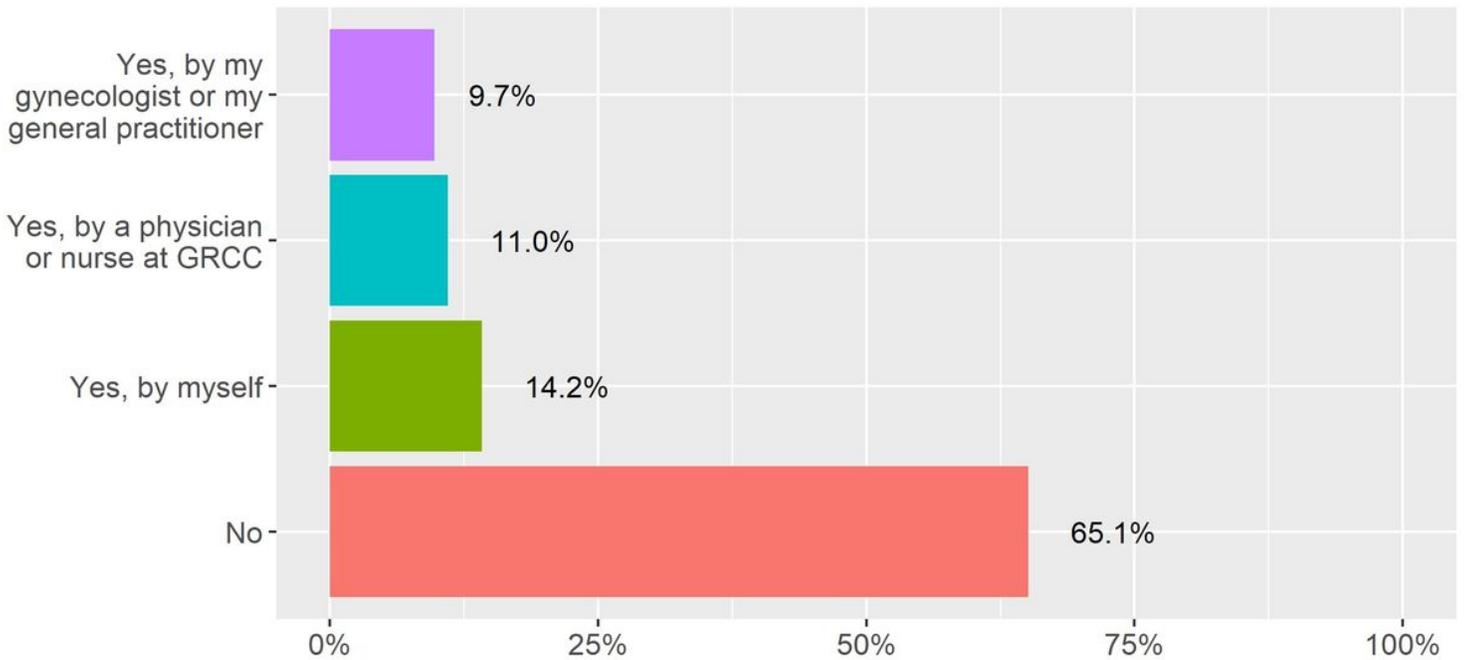


Figure 2

Distribution of answers to the question 22 : "The topic of sexuality was addressed in the consultation" in survey participants. Abbreviation: GRCC = Gustave Roussy Cancer Center

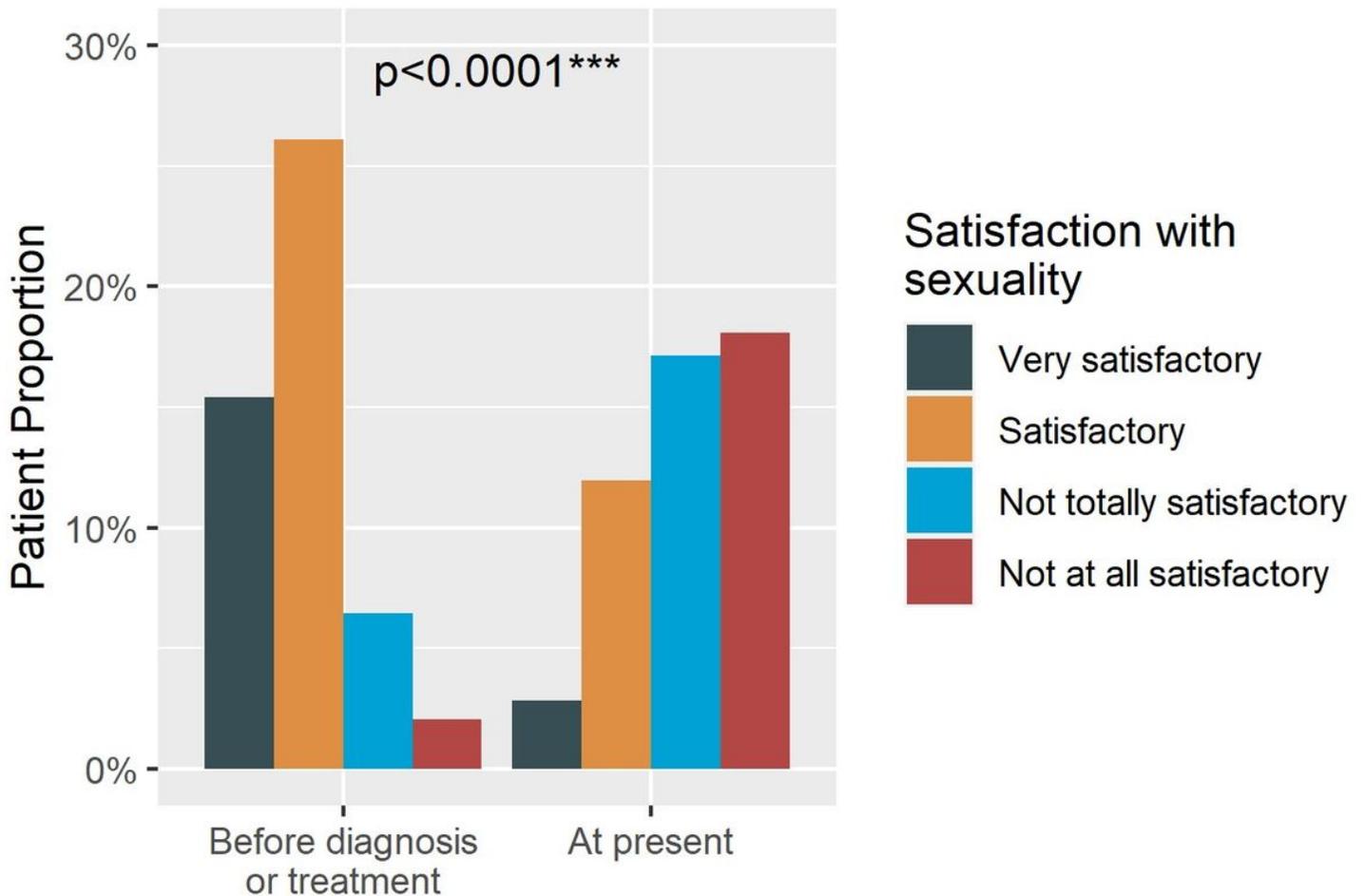


Figure 3

Retrospective self-reported satisfaction with sexuality before BC diagnosis and/or treatment and at present a Abbreviation: BC = Breast Cancer a p-value was computed using a McNemar test for paired values.

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