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ORIGINAL ARTICLE

Breaking bad news of a breast cancer diagnosis over the telephone: an emerging trend

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Abstract

Purpose This study evaluated how breast cancer diagnoses were shared with patients.

Methods Current members of the Dr. Susan Love Research Foundation's Army of Women cohort were sent one email with a link to a survey assessing how their breast cancer diagnosis was communicated, a description of their support system during treatment, basic demographic information, and breast cancer diagnosis details.

Results Participants (*n* = 2896) were more likely to be given their diagnosis over the telephone in more recent years (OR 1.07, 95% CI 1.06–1.08). Up until about 10 years ago (1967–2006), breast cancer diagnoses were communicated in person more often than by telephone. Since 2006, more than half of participants learned about their diagnosis over the telephone. From 2015 to 2017, almost 60% of participants learned about their diagnosis over the telephone. Among those who heard the news in person, a steady 40% were alone. Characteristics of those who received the news over the telephone included having identified support members, heterosexual identity, and a diagnosis of in situ breast cancer.

Conclusions Receiving a telephone call about breast cancer diagnosis may be the norm rather than the exception in health care today. Trends in practice, as well as current best practices based primarily on expert opinion, may not provide optimal care for women diagnosed with breast cancer. Patient outcome research to guide future practice, such as the impact of modes of delivery of bad news, is urgently needed to determine appropriate patient-centered approaches for notification of breast cancer diagnoses.

Keywords Breast cancer diagnosis · Patient-provider communication · Telephone communication · Bad news

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Much has changed during the twenty-first century regarding the expectations of patients and the practices of physicians when informing patients of their breast cancer diagnosis. Medical care, historically, has taken a paternalistic approach to patient decision-making, with only recent understanding of the importance of shared decision-making and a patient-centered approach [1]. In a systematic review of the literature on the communication of bad news to cancer patients, four aspects of patient preferences included setting (i.e., in person consultation, sufficient consultation time, and privacy), manner of communicating (i.e., physicians speaking clearly and honestly, avoiding medical jargon, showing images and laboratory data, and providing written explanation), what and how much information to be provided (i.e., told illness was cancer, chance of a cure, effectiveness of treatment), and emotional support (i.e., use supportive language and allow patients to express their feelings) [2].

To date, research has paid little attention to the mode of communicating bad news to patients (e.g., over the telephone, by secure email, or in-person). Recently, some studies have described preferences of patients in learning about their breast cancer diagnosis [2–9]. While many patients might expect to learn about their breast cancer diagnosis through in-person consultation, this does not always happen. For example, in Kuroki and colleagues' study, one quarter of contemporary oncology patients learned about their diagnosis over the telephone [3]. The best mode for delivering bad news based on physicians' judgment, assumptions, convenience, or institutional protocols [10, 11] is a current topic of debate [12], with patients rarely being asked about their preferences [9]. Reports of communication problems by cancer patients have been associated with poor compliance with medical treatment and increased distress [13–15]. Consequently, disparities between physician practices and patient expectations about the mode of bad news delivery may negatively impact breast cancer patient outcomes.

The purpose of this study was to describe the trend in modes of physician communication of breast cancer diagnoses to a cohort of women diagnosed with breast cancer from 1967 to 2017. Additionally, to add to the understanding of what patient factors might be associated with delivery of bad news, we captured demographic and other significant data related to the patient to identify possible associations with the mode of communication utilized by the physician.

Methods

Participants

After obtaining approval from the University of Missouri's Institutional Review Board (MU-IRB) in November 2017, current members of the Dr. Susan Love Research Foundation's Army of Women (AoW) were recruited to participate in the study. The Dr. Susan Love Research Foundation (SLRF) partnered with the Avon Foundation for Women to launch the AoW. The AoW recruits volunteers, with and without a history of breast cancer, who are willing to participate in breast cancer research studies. After obtaining approval from their home institutional review board, researchers submit their proposal to the SLRF. Upon approval, SLRF sends an email to the AoW cohort about the approved study. For the current study, the AoW cohort was emailed a single request (i.e., one email was sent) to answer a brief anonymous survey about demographics and their breast cancer diagnosis via a survey link. Eligible women were US residents able to answer a short questionnaire in English. Elements of consent were included at the beginning of the survey. Informed consent was obtained from all individual participants included in the study. Data were retrieved after 3 weeks, with the majority of responses being submitted within the first week.

Measures

Demographic variables included self-reported month/year of birth, sexual and gender minority status (i.e., lesbian, gay, bisexual, transgender, or something else), race/ethnicity, and current partnership/marital status. Information about their first breast cancer diagnosis included year, stage, and treatment. Specifically, participants were asked, "What kind of breast cancer have you been diagnosed with (check all that apply)?" Options were in situ breast cancer, invasive breast cancer, inflammatory breast cancer, triple negative breast cancer, other (please describe), do not know/not sure. (While lobular carcinoma in situ [LCIS] is not breast cancer, participants completing the survey responded positive to a history of breast cancer when they indicated that they had LCIS. These participants checked "other" and described their breast cancer as LCIS. Because from the patient's viewpoint they did have breast cancer, the participants with LCIS were analyzed and grouped with the patients with ductal carcinoma in situ). How participants received their diagnosis (i.e., Which of the following best describes the situation at the time you received your FIRST breast cancer diagnosis?) was also assessed and the choices included (a) given over the telephone, (b) given in person and went alone, (c) given in person and a spouse or significant other accompanied the participant, (d) given in person and a family member accompanied the participant, (e) given in person and a close friend accompanied the respondent, or (f) other. For those who responded with an "other" response, responses were re-coded if the answer fit one of the pre-defined categories. For example, "It was given to me when I woke up from the biopsy" was re-coded as given in person, alone. For situations in which the husband was told over the phone and relayed the bad news to his spouse, presumably in person, we left this coded as "other." Post-diagnosis support was assessed by asking, “Who did you rely on for emotional support during treatment for your FIRST breast cancer? (check all that apply).” Answer options were my partner at the time, one or more of my parents, one or more of my siblings, other family members, my partner’s family, friends, one or more of my work colleagues, one or more of my ex partners, other (please specify).

Statistical analysis

Descriptive statistics were computed for demographic data, including chi-square analysis and independent *t* tests (for categorical and continuous variables, respectively) to compare the characteristics of participants who received their cancer diagnosis over the telephone versus by another means. A multivariable logistic regression was used to model the likelihood of receiving a breast cancer diagnosis over the telephone based on specific participant characteristics (race, marital status, sexual and gender minority status, and level of support) and cancer/diagnosis characteristics (year, cancer type, number of diagnoses). Odds ratios (OR) and 95% confidence intervals (CI) were calculated. Model discrimination was assessed with the c-statistic and model calibration was assessed with the Hosmer-Lemeshow goodness-of-fit test. Finally, trend lines were plotted to show changing trends in participants’ receiving breast cancer diagnosis by method of delivery (by telephone or other means) and by year of diagnosis. All analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC).

Results

Of the 6432 participants who responded to this survey, 2970 (46%) reported a history of breast cancer. After excluding 74 participants with incomplete data, we were left with a study population of 2896 participants. The majority of the participants were White (93%) and were married/domestic partners/living with a partner at the time of breast cancer diagnosis (81%). Five percent ($n = 134$) self-identified as lesbian, bisexual, or something else (i.e., queer, asexual, polysexual, postsexual, heteroflexible, bi-curious, mostly straight, etc.). The mean and median age was 51 years (range 23–85 years) and participants reported receiving their first breast cancer diagnosis between 1967 and 2017. Sixteen percent ($n = 450$) reported more than one breast cancer diagnosis. A similar percentage (19%) was currently in treatment or within 1 year of completing their primary breast cancer treatment (i.e., surgery, radiation, chemotherapy). The majority of participants (78%) reported their cancer as invasive, stage 1 or 2 (Table 1).

In the multivariable logistic regression model, participants were more likely to be given their diagnosis over the telephone in more recent years (OR 1.07, 95% CI 1.06–1.08) or when receiving an in situ versus a metastatic breast cancer diagnosis (OR 1.73, 95% CI 1.02–2.93). Participants who did not have post-diagnosis support from family, friends, or professional groups were less likely to report receiving their diagnosis by telephone call (OR 0.30, 95% CI 0.13–0.68) compared to those who identified a spouse as a source of support, and participants who self-identified as a sexual minority (OR 0.70, 95% CI 0.48–0.99) were less likely to receive their diagnosis by telephone call than were heterosexual women. Marital status, race, and number of cancer diagnoses were not statistically significant indicators. Model fit was adequate ($p = 0.38$) and discrimination was modest (c-statistic = 0.63) (Table 2).

Further exploration of the notification trends indicated a cross-over affect, with notification by telephone becoming more prevalent in 2006 and afterwards. As seen in Fig. 1, there was a steady rise in use of the telephone to share bad news. This was seen for both non-metastatic invasive breast cancer and in situ (includes LCIS, $n = 31$) breast cancer. Removing LCIS from the in situ category produced a similar trend line. The two other categories of diagnosis (metastatic [$n = 68$] and other type [$n = 14$]) had less stable patterns due to the smaller sample size by year, though combining these data showed that notification by telephone call occurred with about the same frequency as other communication types starting in 2010.

Participants’ comments

A small subset of participants ($n = 121$) indicated that they received notification of their breast cancer diagnosis in some “other” situation. Participants in this group were asked to specify these situations using an open-ended text field. The majority of comments made in the “other” category reflected a more nuanced view of communication by sharing location or procedure at the time of diagnosis delivery (Table 3). About half of these participants received the news in person: either alone, typically immediately after surgery (41%), or with someone else present (13%). The remaining participants received the news either by telephone (21%), from their husbands (9%), or by fax/email/letter (16%). Table 3 provides a selection of comments that illuminated the delivery of the news.

Discussion

Our study of 2896 women diagnosed with breast cancer between 1967 and 2017 found that some aspects of how bad news is being communicated to breast cancer patients have changed over time. Prior to the last decade (1967–2007), about 25% of the participants surveyed here learned of their diagnosis over the telephone, with the remainder being told in person. In the last 10 years (2008–2017), over 50% of the women in the current study learned the news of their diagnosis

Table 1 Characteristics of Army of Women participants, receiving breast cancer diagnosis for their first diagnosis of breast cancer by telephone or not

	All		Other means, mostly in person	By telephone	
	n	%	%	%	*p* value
Overall	2896	100%	49%	51%	
Mean age of first diagnosis (SD)	51.2	(9.7)	51.1 (10.1)	51.4 (9.3)	0.44
Number of breast cancer diagnoses					0.0007
One	2446	84%	48%	52%	
Two	450	16%	57%	43%	
Year of diagnosis					< 0.0001
< 2000	483	17%	71%	29%	
2000–2004	439	15%	54%	46%	
2005–2009	780	27%	47%	53%	
2010–2014	744	26%	39%	61%	
2015–2017	450	16%	43%	57%	
Type of breast cancer					0.54
Metastatic	68	2%	56%	44%	
In situ (includes LCIS)	567	20%	48%	52%	
Invasive	2247	78%	50%	50%	
Other	14	0.5%	43%	57%	
Marital status					0.90
Married	2336	81%	49%	51%	
Divorced	240	8%	50%	50%	
Separated/widowed	100	3%	53%	47%	
Single	220	8%	49%	51%	
Sexual minority status					0.16
Heterosexual	2762	95%	49%	51%	
Sexual minority (e.g., lesbian, bisexual, gay)	134	5%	55%	45%	
Race					0.14
White	2682	93%	49%	51%	
Other race	214	7%	54%	46%	
Post-diagnosis treatment support					0.11
No one	34	1%	74%	26%	
Spouse at the time of diagnosis	415	14%	48%	52%	
Family members only	368	13%	50%	50%	
Non-relatives only	188	6%	47%	53%	
Family and non-relatives	1734	60%	49%	51%	
Professional and family/non-relatives	157	5%	50%	50%	

over the telephone. Among all those who heard the news in person, a steady 40% learned of their breast cancer diagnosis with no one else present at their appointment. Characteristics of those who received the news over the telephone included having identified post-diagnosis support from family, friends, or professional groups; being heterosexual; and being diagnosed with in situ breast cancer. It is noteworthy to mention that this cohort self-enrolled in Dr. Susan Love Research Foundation's Army of Women cohort and therefore these results cannot be generalized to the general population.

Most established protocols for breaking bad news, such as SPIKES [16], BREAKS [17], Kaye's 10 steps [18], and Paciente protocol [19], among others, assume in-person communication. These protocols can be adjusted to consider the mode of communication, but it is not clear if the same best practices are equally effective when communicating bad news by telephone. This is an area in need of attention, as aptly described by Dean and Willis [20].

A small number of studies have reported variability in how the diagnosis of cancer is given and what patients prefer. An Australian study demonstrated the majority of cancer patients (74%) were given their diagnosis in person and 77% of these patients preferred this mode [7]. A more recent study performed in the USA showed a much lower percentage of breast

Table 2 Multivariable logistic regression results for receiving bad news by telephone, Army of Women participants, 2017

	95% CI			
	OR	Low	High	*p* value
Year of diagnosis	1.07	1.06	1.08	< 0.0001
No. of diagnoses	1.06	0.85	1.32	0.62
Cancer type (reference = metastatic)				
In situ (includes LCIS)	1.73	1.02	2.93	0.04
Invasive	1.38	0.83	2.28	0.21
Other	1.82	0.54	6.07	0.33
Marital status (reference = single)				
Divorced	1.03	0.71	1.51	0.87
Married	1.07	0.79	1.44	0.66
Separated/widowed	0.83	0.51	1.36	0.46
Sexual minority versus heterosexual	0.70	0.48	0.99	0.04
White versus other	1.28	0.96	1.72	0.08
Post-treatment support (reference = spouse)				
Family and non-relatives	0.95	0.76	1.19	0.66
Family members only	0.92	0.68	1.23	0.57
Non relatives only	1.16	0.79	1.70	0.44
No one	0.30	0.13	0.68	0.003
Professional and family/non-relatives	0.96	0.66	1.41	0.85

cancer patients receiving the diagnosis in person (39%), whereas 50% of patients preferred the in person option [5]. Timing of breast cancer results seems to be a more important factor to patients than mode of delivery, with patients preferring the mode that gets the results to them as quickly as possible [6, 7, 21]. However, our study found that patients were significantly less likely to receive metastatic breast cancer diagnosis over the telephone than in situ breast cancer diagnosis. We can presume that in-person contact may be the preferred methods for sharing this devastating news by the physicians. One effective strategy to communicate bad news, particularly for terminal diseases as outlined by Sparks and colleagues is comforting. This strategy requires in-person contact [22].

Multifactorial changes in the nature of medical care may support our finding of an emerging trend in receiving bad news over the telephone. The digital age has increased the use of telemedicine for cancer care, especially for patients living far from cancer centers [23, 24]. We can speculate that a high prevalence of mobile phones [25] has changed individuals' expectations of connectivity [26]. Similarly "open notes/electronic medical records," e-health portals, and the federal mandate from the Health Information Technology for Economic and Clinical Health Act (HITECH Act) converge to support messaging from health care providers as well as rapid dissemination of medical results [27]. In fact, the direct release component of the HITECH Act dictates release of test results without health care providers as intermediaries [28, 29]. Consequently, our study suggests that some physicians have decided to talk to their patients about test results sooner over the telephone and before the posting of the test results versus later at a clinic visit.

Further, a vital component of effective doctor-patient communication is developing a therapeutic doctor-patient relationship. One important component of this relationship is information exchange, and the current model is shared decision-making and patient-centered communication [30, 31]. As noted in Table 3, some patients are actively involved in their care and request delivery of bad news over the telephone. This mutual decision between the health care provider and patient about when, where, and how to communicate medical results

Fig. 1 Trends in percentage of participants informed of their breast cancer diagnosis by telephone or not by telephone, between 1967 and 2017

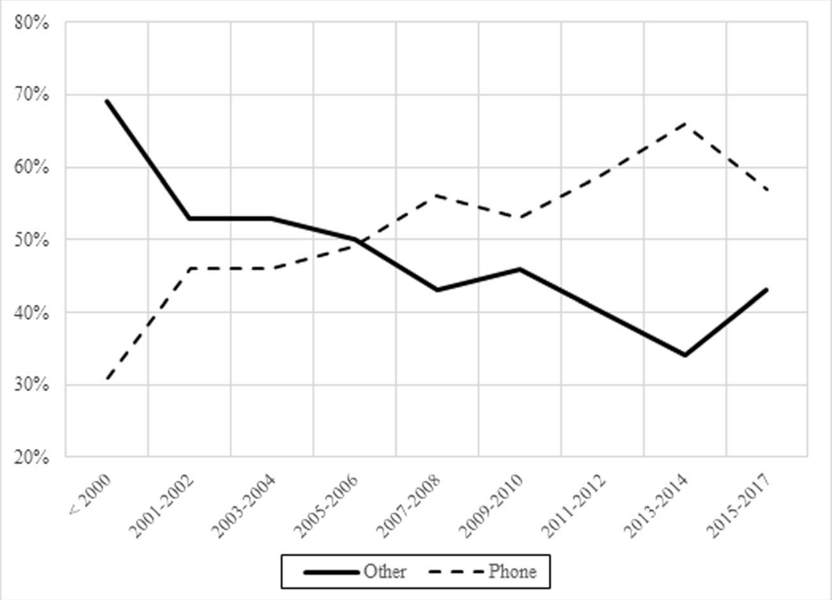

Table 3 Selected comments about how patients were told about their breast cancer diagnosis

Comment	Year of diagnosis	Age	Stage
"Doctor's office called to set up a time for me to come in to go over the biopsy results. When you receive that call you know it's cancerous. No doctor ever takes the time for you to come in to their office for results unless they are bad. So I feel I got the news over the phone alone. However my husband did go with me to the doctor's appointment when I received the official diagnosis."	2009	39	III
"Given over the phone AFTER I'd been assured, the preceding day by a radiation oncologist, that I did NOT have breast cancer. That was bad enough, but it was Grade 3—super aggressive, which was really a shock AND estrogen receptor negative. Another shock."	2007	64	III
"I had results faxed to me."	2013	dk	II
"I received an online notification from my health care provider. I read it online. It was very upsetting."	2009	38	I
"I was mad that they would not tell me over the phone as I was on a business trip and then the first available appointment was 3 weeks afterwards."	2011	54	III
"It came in a letter"	2007	60	II
"It was from my doctor who knew me extremely well so was willing to tell me on the phone."	2009	56	II
"It was given to me in person by my oncologist with family members on a conference call. So that my family was present and able to ask questions"	2015	74	II
"It was given to me via email through my clinical site. My husband was gold at the time of the biopsy that the surgeon suspected it was cancer but he did not share that with me."	2009	62	I
"My husband gave me the diagnosis. He had talked to my surgeon on the phone and got the diagnosis. Then, my husband came to my office and gave me the news."	1997	53	dk
"My mother told me. They called her with the results of my biopsy since I was at work that day."	2016	38	II
"Over the phone by a nurse—horrible experience"	2017	41	I
"Over the phone, but MY choice!"	1999	53	0
"Radiologist told me at mammogram, was by myself. Results of biopsy with husband at surgeon."	2016	42	IV
"The doctor called my husband and I found a new doctor!"	1993	45	I
"They called and said the results were in and made an appointment for that day, but I told her I wanted to know right now over the phone (even though I was still going to the appointment later that day) and she reluctantly told me over the phone."	2004	46	I
"They forgot to call. I got the news in a form letter."	2014	54	I
"Told it was cancer in person. Told it was stage IV (after PET scan) by phone."	2010	33	IV
"We were on vacation so requested a call."	2016	54	I

is a natural sequel to the cultural shift toward patient autonomy and shared decision-making in this digital age. However, to date, little evidence-based research is available to guide physicians on best practices; yet, our study suggests clinical practice is embracing this change.

Until it becomes standard practice to ascertain patient preferences for when, where, and how they wish to hear about their breast cancer diagnosis, the risk of not meeting patients' expectations remains high. For example, when German patients were asked to evaluate their experience with physicians using the SPIKES protocol, most patients reported receiving the bad news along with the other recommended elements of the SPIKES protocol in a single encounter [14]. About half of the patients were dissatisfied with the single encounter and indicated a preference for another appointment to process the news and make plans.

Beyond identifying a clear pattern of more participants receiving their breast cancer diagnosis by telephone over time, we were not able to determine if this emerging communication pattern is being driven by participants' preferences or by physicians' preferences. This is an area in need of exploration. Because women who were given the news over the telephone were more likely to have identified support members and had a diagnosis of in situ breast cancer, it is possible physicians are willing to give bad news over the telephone to patients perceived as having a better prognosis and identified support. Our study did not support prior research that sexual minority women are more likely to receive a breast cancer diagnosis over the telephone [32]. This inconsistency may be due to selection bias and/or the relatively small sample size of sexual minority women in this study. Among the 121 participants who selected the "other" category to describe their notification experiences more fully, the range of responses described a myriad of situations in which the news was delivered. In a few cases, the choice of receiving the news by telephone was explicitly requested by the patient and, sometimes, these situations were met with hesitation by physicians. The reluctant physicians may have felt the best practice for delivering bad news was in person, and/or felt uncomfortable performing this task over the telephone. It is also possible that participants wishing to receive the news over the telephone might prefer that mode of delivery over waiting longer to hear the news in person. These speculations highlight the need for a more comprehensive understanding of the match between patient preferences and provider practices, and a better understanding of the potentially competing desires to hear the news in person but also to hear it as soon as possible.

Receiving the news of a cancer diagnosis over the phone also raises questions about the ability of physicians and patients to use and read nonverbal cues and context within which the patient is receiving the news. Patients prefer physicians to deliver bad news at an unhurried pace and to demonstrate empathy and emotional support [2], which might be more difficult to achieve, or perceive, over the telephone. In addition, a provider relaying bad news in person knows whether the patient is alone at the appointment or not. A provider on the telephone has less information about the situation in which the patient is receiving the news. Unless the patient is on a speaker phone, communicating this information to other important family members is not straightforward. Similarly, with the proliferation of cell phones as the contact mechanism, calling increases the chances that a cancer diagnosis is disclosed in an undesirable setting, such as while the patient is driving, in a public place, or at a work setting.

Limitations need to be considered when evaluating these results. The Army of Women is a self-selected cohort of women either diagnosed with breast cancer or interested in breast cancer research, who voluntarily enroll and agree to consider research requests. As the majority of women were White and heterosexual, the results from this study may not reflect racial/ethnic or sexual minority women's experiences. Another characteristic of our population that influences the generalizability is that the mean (and median) age was young at 51 years, whereas the median age of breast cancer in the USA is 62 years [33]. All the data were self-report, which may have introduced some errors in recall. In addition, there were women who self-identified as having been diagnosed with breast cancer who also reported a diagnosis of LCIS. This response may represent a change in the understanding of LCIS over time but also may indicate unsuccessful patient education. Participants were asked for details about their first breast cancer diagnosis, but some participants who have had more than one breast cancer diagnosis may have reported on their most recent breast cancer diagnosis. The additional information provided by the 4% of participants who selected the "other" category when asked how they received their diagnosis reflects only those participants who chose to provide more details. Information gleaned from these responses, albeit rich in context, may not reflect the experiences of this cohort or of breast cancer patients in general.

Future research should move beyond study designs that rely on patient recall or gather data on physicians' good intentions. Surveys and qualitative interviews occurring months and years after the delivery of bad news likely also reflect the emotional experience of the patient. Additionally, physicians often know the right answers to give in terms of best practices for the delivery of bad news but many express a desire for more training to do so effectively [34]. A longitudinal design following the patient-physician (and the cancer health care team's) relationship from point of breast cancer diagnosis to end of treatment may aid in documenting what occurs in real time and improve our understanding of the influence of bad news delivery on distress and outcomes over the course of treatment. Additionally, observational study of audio- or video-recorded patient encounters with physicians when bad news is delivered both in person and via telephone would allow for a more accurate and richer description. This could further aid in training physicians about effective use of best practices given the particular mode of delivery the patient prefers.

In summary, this study provides empirical data on the changing trends in how women with breast cancer are being informed about their disease. Receiving a telephone call about the news may be the norm, rather than the exception, in health care today. Areas in need of further exploration include best practices for delivery of bad news over the telephone, understanding the drivers in this emerging trend in communication, linking the type of communication style to health outcomes, and exploring the potential influence patient preference has on how bad news is delivered. Finally, patient outcome research to guide future practice, such as delivery of bad news, is needed as trends in practices and current best practices based primarily on expert opinion may not be providing optimal care for women diagnosed with breast cancer.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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