The Breast 23 (2014) 743–748

Contents lists available at ScienceDirect

The Breast

journal homepage: www.elsevier.com/brst

Original article

Online support: Impact on anxiety in women who experience an abnormal screening mammogram

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ARTICLE INFO

Article history:
Received 21 April 2014
Received in revised form
25 June 2014
Accepted 5 August 2014
Available online 3 September 2014

Keywords:
Screening
Anxiety
Mammography

ABSTRACT

Objectives: To determine whether an online support tool can impact anxiety in women experiencing an abnormal mammogram.
Materials and methods: We developed an online support system using the Comprehensive Health Enhancement Support System (CHESS) designed for women experiencing an abnormal mammogram as a model. Our trial randomized 130 of these women to online support (the intervention group) or to a list of five commonly used Internet sites (the comparison group). Surveys assessed anxiety and breast cancer worry, and patient satisfaction at three important clinical time points: when women were notified of their abnormal mammogram, at the time of diagnostic imaging, and at the time of biopsy (if biopsy was recommended).
Results: Study participants in the intervention group showed a significant decrease in anxiety at the time of biopsy compared to the comparison group ($p = 0.017$). However, there was no significant difference in anxiety between the intervention group and the comparison group at the time of diagnostic work-up. We discontinued assessment of patient satisfaction after finding that many women had substantial difficulty answering the questions that referenced their physician, because they did not understand who their physician was for this process of care.
Conclusion: The combination of the inability to identify the physician providing care during the mammography work-up and anxiety effects seen only after an interaction with the breast imaging team may indicate that online support only decreases the anxiety of women in concert with direct interpersonal support from the healthcare team.

Introduction

Screening mammography reduces breast cancer mortality through earlier detection of smaller, more curable cancers [1]. Of all screening mammograms, approximately 10% will be found to be abnormal and require additional evaluation, but only 0.1%–0.5% of women who undergo screening mammography will actually be diagnosed with breast cancer [2]. This means that despite a highly specific screening test (>90%), the vast majority of abnormal exams are false positives. False positive examinations lead to additional studies, such as diagnostic mammograms and ultrasound, and even biopsy procedures [3]. This can result in anxiety, which could have a negative impact on future screening behaviors [3–6]. Therefore, an intervention that decreases anxiety would be useful.

The impact of an abnormal mammogram on women's psychological well-being is an active area of research [3,4,6–10]. Some women develop considerable psychological distress, particularly anxiety [3], at the time of abnormal mammography [11–14]. For example, 16% of women felt certain they had breast cancer [15], and about 30% felt "very anxious" after receiving the letter notifying them of an abnormal result (the "recall letter") [15]. Prolonged waiting periods between the time of the screening mammogram and the diagnostic mammogram can also increase anxiety [16,17]. The literature reflects variable findings regarding how long anxiety continues after false positive mammography, with some studies

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http://dx.doi.org/10.1016/j.breast.2014.08.002
0960-9776/

reporting a range from several months to as long as 3 years [13–15,17–23]. During the diagnostic workup, women rely on social support networks [24] and educate themselves about breast cancer to manage their anxiety and prepare for a diagnosis [25–27], suggesting that tailored information in the form of an online support module may help women during this period, when few quality resources are available and many questions remain unanswered. Interaction with a healthcare provider [17,28], but not basic informational materials [29], is effective at reducing anxiety.

The Internet has become a primary source for health information and emotional support for patients [30]; however, the information provided is often of poor quality [31,32] and patients frequently remain without information until interacting with healthcare staff. The Comprehensive Health Enhancement Support System (CHESS) has been shown to improve women's ability to seek out information and obtain support after a breast cancer diagnosis [33]. CHESS is a computer-and web-based tool that incorporates searchable health information, an interactive component that guides patients by making suggestions and giving feedback, and a module that links them electronically with other patients with breast cancer. For this project, we implemented an online support module (Early CHESS), which modifies the health information features of CHESS to focus on women with abnormal screening mammogram results.

The purpose of this pilot study was to evaluate the impact of Early CHESS on women with an abnormal screening mammogram by assessing anxiety, breast cancer worry, and patient satisfaction with the radiologist.

Materials and methods

Clinical process

The study procedure was integrated into the standard clinical process at the University of Wisconsin (UW) Breast Center (see Fig. 1). After a screening mammogram is performed on an asymptomatic woman, the images are evaluated by a radiologist. A decision is then made to either return the patient to routine screening or recall the patient for additional imaging. If diagnostic mammography is indicated to work-up an abnormality, the patient receives a phone call from a nurse, is sent a recall letter, and the primary care physician is notified. At the follow-up appointment, a diagnostic mammogram is performed, providing the first opportunity for the patient to interact in person with clinical staff since the receipt of the recall letter (Fig. 1). After the radiologist evaluates the diagnostic mammogram, a decision is then made to return the patient to routine screening, recommend a six-month follow-up, or recommend a biopsy. A biopsy is recommended when the findings on mammography are concerning and tissue sampling is warranted for further evaluation. At the UW Breast Center, patients always meet with a radiologist if a diagnostic ultrasound is performed or if a biopsy is recommended.

Power and sample size

Based on our previous experience with online support for breast cancer, we estimated a 10% drop out rate over the study period. We also anticipated that some assessments would be missing for other reasons. Given an anticipated moderately small treatment effect size of 0.4 s.d. with a power of 80%, a one-tailed alpha of 0.05, and baseline-outcome measure correlations of 0.60, we concluded that we would need a completed sample size of 102. We thus decided to recruit a total sample of 130, in order to accommodate for attrition or missing data.

Recruitment

After Institutional Review Board (IRB) approval was obtained, recruitment was conducted from June 2010 to November 2011. Inclusion criteria included: women who were >21 years old, able to read and understand English, had access to the Internet, and were being recalled for diagnostic imaging after a screening mammography. The women were invited to participate by nurses who notified them of their abnormal mammogram, which occurred prior to the receipt of the recall letter notifying them of their abnormal results. After permission was obtained, a research staff called each woman, explained the details of the study, answered questions, obtained verbal consent, collected contact information and demographic data, and the baseline survey questionnaire was completed. At the time of enrollment, the research staff confirmed the participant's recall appointment time and met the patient at the UW Breast Center to complete the second survey and obtain written consent.

Intervention

Once the research staff completed verbal consent and the baseline telephone survey, participants were randomized via a computer-generated list that was accessed by the study director. Each participant was informed of her randomization group. The comparison group received a list of five credible breast imaging websites (see Appendix 1) via email. Subjects randomized to the intervention (Early CHESS) group received an email with instructions for accessing the Early CHESS website, including login information.

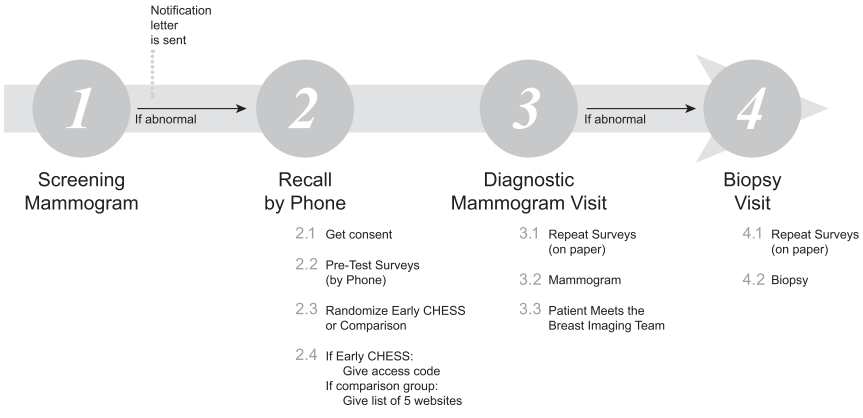

Fig. 1. Timeline and assessments.