



Original article

Perspectives on Mammography after Receipt of Secondary Screening Owing to a False Positive



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A B S T R A C T

Background: The utility of mammography screening as an efficacious tool for early detection is being contested owing to the risk of potential harms, including psychological distress and exposure to unnecessary procedures associated with false-positive (FPs) results and overdiagnosis. However, there is little research regarding women's experiences, values, or preferences for participating in mammography programs. Our aim was to explore women's actual experiences of a FP mammography screen and their perceptions of the value, risks and benefits given their recent experience.

Methods: We conducted semistructured interviews with 40 women who experienced a recent FP mammogram. Interviews were recorded and transcribed verbatim. A directed content analysis was used to identify and explore primary themes. Knowledge of breast cancer risk was also assessed.

Findings: Receiving a FP mammography screen generated significant worry among 60% (n = 24) of women. Yet 70% maintained that mammography screening was necessary despite the worry incurred. Women also described the experience as stimulating greater interest in additional cancer prevention activities (32.5%; n = 13) and one-third discussed needing more information about the risks and benefits of mammography screening. Less than one-quarter of women (22.5%; n = 9) correctly identified a women's lifetime risk of developing breast cancer; 20% (n = 8) overestimated, and 57.5% (n = 23) underestimated this risk.

Conclusion: Women reported needing more information about the risks and benefits of mammography screening, but also considered FP results an acceptable risk. Further, our results suggest that breast cancer screening programs may provide a unique opportunity to deliver additional breast cancer prevention interventions.

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Introduction

In a survey of more than 1,000 adult U.S. women, breast cancer was identified as the most feared disease ([National Heart Lung and Blood Institute \[NHLBI\], 2012](#)). Although not the most common killer of American women, it is the most common cancer diagnosed in women and is expected to result in 40,000 deaths in 2014 ([National Cancer Institute \[NCI\], 2014a](#)). Breast cancer has been the subject of a concerted campaign over the past 20 years to educate and motivate women to obtain regular

mammography screening. However, the efficacy of regular screening is now under debate. In 2009 the U.S. Preventive Services Task Force (USPSTF) rescinded recommendations for mammography screening for women aged 40 to 49 recommending women begin to screen biennially at age 50. Neither the American Cancer Society nor the NCI have altered their recommendations ([American Cancer Society \[ACS\], 2013](#); [NCI, 2014b](#)). The scientific evidence supporting these different recommendations is the same; however, the interpretation of the balance between risks and benefits of mammography is markedly different. Such contradictions have led to much public and professional confusion regarding the appropriate use of mammography screening, including age of initiation and frequency of mammography.

The USPSTF changes were meant to address increased risk of psychological distress resulting from false-positive (FP) results,

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overtreatment and increased radiation exposure (Nelson et al., 2009). FP outcomes require further investigation for example, additional office visits, imaging, or diagnostic biopsies (Barton et al., 2001; Elmore et al., 1998). In the short term, FPs can increase cancer worry, anxiety, and perceived susceptibility to breast cancer (Armstrong, Moye, Williams, Berlin, & Reynolds, 2007; Barton et al., 2001; Gram, Lund, & Slenker, 1990; Salz, Richman, & Brewer, 2002). Such short-term effects are unfortunate, however unsurprising; therefore, it is important to consider psychological harms in terms of their duration of effect. Longitudinal studies of FP effects have found mixed results, owing in part to differences in the rigor of the measures used and study duration. In the United States, women who experienced a FP were more likely to return for future screening than women with normal results (Brewer, Salz, & Lillie, 2007; DeFrank et al., 2012). Although some studies have reported no long-term effects (Cockburn, Staples, Hurley, & De Luise, 1994; Lampic, Thurfjell, & Sjoden, 2003; Sandin, Chorot, Valiente, Lostao, & Santed, 2002), others suggest that women experience increased breast cancer anxiety and risk perceptions as long as 3 to 5 years after a FP (Brodersen & Siersma, 2013; Lindberg, Svendsen, Dømggaard, & Brodersen, 2013). Of note, there is a consistent finding that, despite increased anxiety, women retain their trust in mammography screening and one study found that the FP actually increased women's feelings of personal responsibility for their health (Brewer et al., 2007; Solbjør, Forsmo, Skolbekken, & Saetnan, 2011).

In addition to the risk of FPs, mammography screening also identifies ductal carcinomas in situ (DCIS), a noninvasive cancer limited to the milk duct. Because there is no current method of determining the probability or timing of DCIS progression into invasive cancer, some women undergo unnecessary treatment. Estimates for the number of cases of DCIS that would never become invasive range from 30% to 50% (Gotzsche & Nielsen, 2009; Jorgensen & Gotzsche, 2004). Critics of mammography question whether these associated harms may be too great in relation to the number of true positives detected through mammography (Bleyer & Welch, 2012; Jorgensen & Gotzsche, 2004).

The decision to participate in mammography screening given the kinds of risks ascribed (i.e., temporary psychological discomfort and the potential for unnecessary testing and treatment) are no different than the consequences of other screening and diagnostic procedures associated with modern health care. Instead, this represents an important example of how to honor individual values and preferences under circumstances of medical uncertainty. Even as concepts such as shared decision making and patient-centered care are becoming increasingly popular, it is noteworthy that little work has been done to understand women's knowledge, values, and attitudes about the risks and benefits of mammography or how to engage them in actively participating in decision making about preventive screening.

Women's decisional preferences may not be congruent with the USPSTF members. In a national survey assessing women's knowledge of mammography screening, 92% of women believed mammography could not harm women without breast cancer, experiencing FP screen results were acceptable risks, and only 6% of women had any knowledge of DCIS (Schwartz, Woloshin, Sox, Fischhoff, & Welch, 2000). The purpose of our study was to qualitatively explore women's actual experiences of a FP mammography screen and their perceptions of the value, risks, and benefits associated with mammography given the context of the FP experience.

Methods

Identification and Participant Recruitment

Women who received a FP mammogram were recruited from a mammography screening clinic in an academic hospital in Virginia that maintains an insurance program for uninsured patients. FP was defined as a screening mammogram that required follow-up investigations that were subsequently determined to be negative for breast cancer. Women were considered eligible if they were aged 40 to 75 years, had experienced a recent (<3 months) FP mammography result on a screening mammogram, had no history of cancer, and were cognitively able to participate in the interview (as determined by the clinic physician). Potential participants were identified using medical charts assessed on a weekly basis by a clinic staff member. Using a standardized data abstraction form, patients who received a final breast reporting-imaging and data reporting system classification of negative or benign findings on follow-up testing for a screening mammogram were identified. Additional information abstracted included the patient name, age, contact information, and date of initial screening mammogram. Only women who received follow-up imaging were interviewed. No women who had required biopsy were identified or enrolled. Identified women were mailed a letter inviting participation in the study described as an exploration of women's experiences participating in a mammography screening program. We completed 40 interviews with women who attended a breast imaging clinic from April to August 2013 and received a FP screening result. The response rate was 45% and no difference by age was found between women who did and did not participate.

Interviews

Upon consent, women participated in a 1-hour, semistructured interview. A trained graduate-level research assistant conducted the interviews. Interviews were audio recorded and transcribed verbatim. Women received a \$25 honorarium for their participation. Institutional review board approvals were attained and informed consent obtained from all participants.

The interview guide was designed to elicit women's narratives regarding their recent FP experience, knowledge of risks related to mammography screening, and reactions to screening guideline contradictions. First, women were asked to describe their initial screening experience and reactions to receiving notification that follow-up testing was required. Thinking aloud and establishing timelines are known to facilitate recall of events (Friedenreich, Courneya, & Bryant, 1998; Maunsell, Drolet, Ouhoumane, & Robert, 2005). Women were asked to recall appointment dates and the number of days between initial and follow-up mammography screens. Using open-ended questions and standardized probes, women were encouraged to describe their emotions, actions, and attitudes during the period of receiving notification to return for follow-up testing to receiving notice that they were free of breast cancer.

In addition to understanding women's experiences of a FP screen, we explored women's reactions to the contradictions in mammography screening guidelines. Women were provided with a short summary of the arguments for and against yearly mammography screening beginning at age 40 years that was developed by NCI and intended for the general public (NCI, 2014b). To assess comprehension, women were asked to explain the information in their own words. Questions or

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