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Perspectives on Mammography After Receipt of Secondary Screening Due to a False Positive

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Abstract

BACKGROUND—The utility of mammography screening as an efficacious tool for early detection is being contested due to the risk of potential harms including psychological distress and exposure to unnecessary procedures associated with FPs and over-diagnosis. Yet 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 semi-structured 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 FPs 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 (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 (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 United States Preventive Services Task Force (USPSTF) rescinded recommendations for mammography screening for women aged 40–49 recommending women begin to screen biennially at age 50. Neither the American Cancer Society, nor the National Cancer Institute have altered their recommendations (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 results, overtreatment and increased radiation exposure (Nelson et al., 2009). False positive (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, 2002). Such short-term effects are unfortunate though 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, due in part to differences in the rigor of the measures used and study duration. In the US, women who experienced a FP were more likely to return for future screening as compared to women with normal results (Brewer, Salz, & Lillie, 2007; DeFrank et al., 2012). While 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 much as 3–5 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 non-invasive cancer limited to the milk duct. As there is no current method of determining the probability or timing of DCIS progression into invasive cancer, some women will experience unnecessary treatment. Estimates for the number of cases of DCIS that would never become invasive range from 30–50% (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 mammography risks and benefits or how to engage them in actively participating in preventive screening decision making.

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 40–75 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 (BI-RADS) classification of negative or benign findings upon 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 during April–August 2013 and received a FP screening result. The response rate was 45% and no significant difference by age was found between women who did and did not participate.

Interviews

Upon consent, women completed a one-hour semi structured 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 also 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 National Cancer Institutes and intended for the general public (NCI, 2014b). To assess comprehension, women were asked to explain the information in their own words. Questions or misunderstandings were discussed and rectified. Women then provided their opinions and attitudes regarding the information.

Finally, two aspects of knowledge regarding breast cancer and screening risks were assessed. Women were asked to assess the lifetime risk of developing cancer for the average women and provided four choices: 1 in 3; 1 in 8; 1 in 10; 1 in 100. This question has been used previously (Linsell et al., 2010). Women were also asked if they had ever heard of ductal carcinoma in situ (DCIS) (yes/no). As women had all experienced a FP screening result we did not ask about knowledge regarding FP risks.

Analysis

Verbatim transcripts were content analyzed using the qualitative data analysis program MaxQDA ("MaxQDA," 2013). Using a directed content analytic approach (Hsieh & Shannon, 2005), initial coding categories were derived from the literature and the research objective (Armstrong, Moye, Williams, Berlin, & Reynolds, 2007; Barton et al., 2001; Gram, Lund, & Slenker, 1990; Salz, 2002; Schwartz et al., 2000). The initial coding categories were: receiving a call back; effect of the FP experience; attitudes regarding mammography and reaction to screening guideline contradictions. Iterative analysis, line by line coding and memo writing enabled a deeper exploration of the initial coding categories and resulted in a final set of 2 primary themes: *Experiencing a FP* and *Understanding the value of mammography*, the first had 4 domains and the second had 2 domains. The lead author, who also conducted the training of the interviewers, completed the data coding and analysis.

RESULTS

Demographics

Forty interviews were completed among women aged 40–68 years (median=49 years). Nearly half of the women interviewed (47%; n=19) had completed university or post graduate training and the majority had health insurance coverage either privately (n=27; 67.5%) or through Medicare or Medicaid (n=6; 15%). Less than 25% reported incomes below \$30,000 and 45% of women were African American. Full demographics are displayed in Table 1.

Experiencing a FP

Iterative analysis identified four domains of the primary theme, *Experiencing a FP*: 1) breast cancer worry, 2) worrisome but necessary, 3) encourages healthy behaviors and 4) clinician diligence. These subthemes represent the reactions and emotions women experienced during the period of time between receiving the request to return for follow-up screens and receiving news that they were cancer free.

Cancer Worry—All of the women described feeling some level of worry upon receiving news that follow-up testing was required, however 24 (60%) women described feeling extremely or significantly worried. Descriptions consisted of feeling convinced that a breast cancer diagnosis was imminent and fears regarding who would be responsible for their young children or other family members. Words that women used to describe their feelings were indicative of very strong negative emotions and included: dread, scared, frightening, terrified, anxious and panic. The following quotes demonstrate the strong, negative descriptions these women provided.

“I was pretty terrified. I mean, my initial thought was ‘Oh I have breast cancer’!”
Participant #63

“It was very, very, very frightening that they wanted to see me as soon as possible. The language, yeah, threw a wrench in my day. So going back, I was very apprehensive. I was concerned that I would get a really bad, like results and they would start talking about breast cancer” Participant #42

Not all women felt significantly worried; 16 (40%) women described feeling minimally or not worried that the initial screen may be indicative of breast cancer. Instead these women described feeling confident that it did not. Women who felt less worried did not use strong, negative emotive words to describe their reactions. Instead these women discussed feeling less concerned because this was something they had all experienced either personally with previous mammography screens. The previous experiences described were primarily their own, but women also talked about their awareness of other women’s similar experiences. These experiences enabled women to temper their own worry about the request for additional screening.

“I didn’t really get worried at all. I was kind of like, ‘Oh OK’. I’ve had enough friends that have had a similar experience. It’s been nothing. Or my mother...she said that always happens to her.” Participant #16

“That’s going for more testing. It’s been so frequently that it wasn’t of a concern”

Participant #36

This group of women also talked about feeling annoyed at the procedure for mammography screening, given their history of FPs. It was felt that steps should be taken to rectify the need to come to an additional appointment. Several women suggested the clinician review the mammography screens during the initial appointment. Women who had experienced an MRI on their follow-up visit were interested in knowing why MRI was not used in place of the usual screening technology.

Not terrible. I was more upset because I felt like they need to do this [additional screens] when you come in for your screening mammogram. Especially if you have a history, which I have had biopsies, if you have that kind of history don’t send me on my merry way. Take a look at ‘em and do whatever has to be done then. Get it over with.” Participant # 27

As some women reported greater or lesser worry resulting from the request for follow up, we further explored whether classifications of worry were related to the frequency with which women discussed each of the remaining theme domains. Table 2 displays the frequencies for the domains discussed by level of breast cancer worry expressed in the interview.

Worrisome but Necessary—The majority (n=28; 70%) of women reported that regardless of the level of worry incurred by a FP mammogram, the importance of participating in mammography screening remained. Women viewed the benefits of participating in mammography screening, namely the reassurance that they were free of breast cancer, as worth any worry caused by the follow-up request. In particular 16 (40%) women specifically mentioned that they suffered no residual worry after receiving news that the follow-up screens were cancer free. The following quotes illustrate these comments:

“OK, let’s do the re-screening, you know? I feel like, the benefit of that would be more important than the risk of getting information that you might have something wrong and you really don’t” Participant #63

Encourages Healthy Behavior—For some women (n=13; 37.5%) the FP experience stimulated a greater interest in breast cancer prevention behaviors. These women discussed how the experience made them re-evaluate their current behaviors like smoking, diet and continued screening and think about making healthy lifestyle improvements to protect against breast cancer. Similar to the action of participation in mammography screening, these women viewed lifestyle changes as specific positive actions that gave them some control over their breast cancer risk.

“Emotionally, it was [a]close call. It was a wakeup call. And so, you know you can’t come away with that without feeling different. I-I definitely felt um, much more aware of my mortality and appreciative of the clean bill of health.”

Participant #9

“Cuz it is crucial to my health you know [what I] mean, because I don’t wanna die from cancer. You know [what I] mean? And I’ve already smoked the cigarettes so I

shouldn't even be smokin those but you know, I don't want nothin to happen to me, you know?" Participant#44

Clinician Diligence—Some women (n=8; 20%) felt that the FP experience was an indication of clinician diligence. Only one woman expressed distrust regarding the final outcome and sought a second opinion. These women reported feeling that they were especially well cared for, that the clinician cared for them as an individual and were reassured that a potential breast cancer would not be overlooked.

"You know, if they see something and they think it's something there then that's letting me know they're on top of their job and doing what they're supposed to do because they detected it right? ...They took their time and they really went into it... we gotta call her back in, we gotta do this work, we gotta do these pictures. That let's me know that they are really concerned, that they're really here to help me." Participant #60

Understanding the Value of Mammography

The second primary theme identified in the qualitative analysis was comprised of two domains: 1) Age 50 is too late, and 2) Women need more information. These subthemes focused on the women's fear of developing breast cancer and lack of understanding regarding the risks and benefits of mammography screening. These conversations were stimulated by the information describing current screening controversies that was adapted from the NCI Factsheet.

Aged 50 is too late—Upon discussing the reasons for the screening recommendation discrepancies, 57.5% (n=23) of the women felt that waiting until aged 50 years to begin receiving regular mammograms was too late. There was confusion and distrust expressed regarding why some health professionals would choose to withhold mammography screening. The women described feeling vulnerable to developing breast cancer in their 40's. The fear expressed was that these breast cancers would not be detected until it was late stage or that an aggressive breast cancer would be missed entirely. Many women described examples of women they knew personally or had heard about that had been diagnosed with breast cancer in their 40's. Only 10% (n=4) of women stated that waiting until age 50 years was more appropriate, all of whom were over 50 years.

"Because I've been affected by so many friends with it, it's hard for me to be an advocate of 50 being the baseline. I understand the science of it, but I'd rather have to go through these anxious periods than wake up at 50 and you know, have something that's been there for 5 to 10 [years]. I just think there's too many people affected by this disease to go to 50." Participant #17

Women need more information—After discussing the guideline discrepancies, one third (n=13) of the women discussed the need for more information to enable better decisions and improved expectations regarding participation in mammography screening. Women wanted more information about their personal risk factors for obtaining a FP result and the likelihood of experiencing a FP. It was felt that knowing this information could

decrease anxiety when follow-up screens are requested. Women also wanted more information regarding their personal risk of developing breast cancer. As part of their discussions describing the need for more information, women noted the difficulty they experienced finding trusted information and felt that it should be provided by health care providers recommending or performing screening.

Well, like I said, I didn't know anything about the fatty tissue and you know how they were saying it tends to be more dense...and I think maybe they should've did a handout, gave me something like a handout explaining it, before I did [the mammogram]. Participant #75

Knowledge of Risks

Closed ended questions assessing two knowledge items regarding lifetime risk of developing breast cancer for a woman at normal risk and whether they had ever having heard of DCIS (as a marker of knowledge of risks associated with mammography) found significant gaps in women's knowledge. While 22.5% (n=9) of the sample correctly identified a women's lifetime risk of developing breast cancer as 1 in 8, 20% (n=8) overestimated and 57.5% (n=23) underestimated this risk. In addition, only 17.5% (n=7) of the women had ever heard of DCIS, despite having received mammography screening.

DISCUSSION

This study has expanded previous findings by exploring women's perceptions and attitudes toward FP screens in a diverse sample of women. While many women reported experiencing significant worry upon receiving notification of the need for follow-up, many did not. The majority of women reported no change in their attitudes regarding the importance of mammography as a tool for early detection. Further, women also reported a renewed interest in healthy behavior modifications. Finally, we found that the women themselves identified a lack of risk/benefit information as problematic, a finding that was reinforced by the low proportion of women (17.5%) who reported having heard of DCIS, a potentially significant mammography risk.

Attending screening is a tangible action that provides women with a sense of control over their breast cancer risk. Cancer worry has been shown to increase participation in cancer screening (Hay, McCaul, & Magnan, 2006). In our study, women regarded participation in mammography to be worth the risk of experiencing FP results and expressed disagreement with the USPTF's changes in mammography screening recommendations, citing increased feelings of vulnerability and fear of breast cancer. We also found that women who experienced a renewed interest in cancer prevention behavior including continued mammography use and interest in lifestyle change. Others have suggested that FP's may prompt greater adherence to screening mammograms, more time thinking about the benefits of a regular mammogram and health management (DeFrank et al., 2012; Lindberg et al., 2013). Similarly, Rabin and Pinto (2006) found that breast cancer survivors who were concerned about recurrence also engaged in more healthy dietary change (Rabin & Pinto, 2006). We suggest that experiencing a FP mammogram may be interpreted as a 'close call' thus increasing information salience regarding modifiable breast cancer risks and potentially

stimulating behavior change. Although not diagnosed with breast cancer, women who have experienced a FP may begin to think about their breast cancer risk in a more concrete way as compared to women who have not received a FP, thus increasing the salience of prevention information. Combining lifestyle interventions with population health screening programs for cervical and colon cancers have shown promise as the screening session acts as a 'cue to action' for other preventive behaviors (Senore, Giordano, Bellisario, Di Stefano, & Segnan, 2012). Future studies should investigate whether the experience of a FP represents an optimal time to present women with additional lifestyle modification interventions.

Interpreting a FP result as an indication of physician diligence was surprising. Henselmans et al., found that experiencing a FP mammogram and waiting at least two weeks for follow up was associated with increase distrust in the final outcome (Henselmans, 2009). Only one woman in our study distrusted her final diagnosis and sought a second opinion. This may be because wait times in our study were minimal (typically less than one week). Thus, it is possible that shorter wait times limit the experience of anxiety and distrust in the eventual negative finding.

Our study sample was well educated with high income and health insurance coverage. This is unsurprising given that participants in cancer screening programs typically report high socioeconomic status, which enables greater access to health information and services (Schueler, Chu, & Smith-Bindman, 2008). Still, most women had never heard of DCIS, and one third wanted more risk/benefit information. There was also frustration regarding the follow-up process, which could indicate further patient information gaps. Women who had experienced previous FPs questioned the procedures and suggested that scans be read during the appointment; those who received an MRI upon follow-up wondered why MRIs were not used as a routine screening tool. Providing information about the risk of experiencing a FP and what that might mean regarding follow-up procedures can help women to make more informed decisions about participation as well as potentially reducing the anxiety and/or frustration a FP result may cause.

This study has limitations. One member of the research team completed data coding. However, the research team discussed results and the findings reported here are in line with what is reported in the literature (Brewer et al., 2007; Lindberg et al., 2013; Schwartz et al., 2000). None of the women experienced a recent biopsy and it is unknown how many might have experienced a biopsy in the past. Thus the attitudes and values of women who experienced a more invasive follow up procedure could be different from women who only experienced noninvasive procedures. Further, women who do not currently participate in mammography screening may have different views regarding the risk/benefit ratio of mammography screening. Including women who have had previous FP but who choose to continue screening may represent different attitudes than women who choose to stop screening. Yet, the purpose of this study was to assess women's experiences with a recent FP among a group of current screeners, therefore we did not include women who ceased screening after a prior FP experience. In addition, many women in our sample experienced a FP for the first time and still reported the necessity of continued mammography screening despite negative FP experiences. Finally, recruitment occurred from one clinic and included only 40 participants, which may impact generalizability as other clinics may introduce

additional mediating variables (e.g., longer wait times, different patient population, staff interactions). However, the sample size was adequate to reach saturation of themes for this study.

As one of the first to qualitatively explore and give voice to women's experiences of a FP screening result, these results provide insight into women's opinions regarding the acceptability of mammography related risks, a viewpoint that has been notably absent from professional debates. In addition, due to the clinic location in an urban academic hospital providing indigent care, the participant sample represents a more diverse group of women than prior studies (Brewer et al., 2007; Schwartz et al., 2000) thus contributing new information to the literature.

CONCLUSIONS AND PRACTICE IMPLICATIONS

Given the USPSTF recommendations that women weigh the risks and benefits of mammography screening when making decisions about screening initiation and frequency, it is critical to understand whether current screeners are aware of these risks and benefits. Our work indicates that women do not have the information necessary to make informed choices (e.g., an understanding risk probabilities and potential ramifications associated with FP or DCIS). We also found that while many women do report significant worry associated with experiencing a FP screening result, this worry is temporary, deemed acceptable by the women, and does not effect all women. In fact, the worry generated by the FP experience may serve as motivator for engagement in additional preventive behaviors.

This work has implications for clinicians and public health practitioners. It is clear that women require and are demanding more information regarding mammography screening. Future communications should focus on general information regarding breast cancer risk and mammography risks and benefits while also enabling women to better understand their personal risks and benefits. Finally, these results suggest that the screening clinic may be an innovative opportunity to introduce interventions focused additional modifiable risk behaviors, particularly among women who have experienced a recent FP mammogram.

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Biographies

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TABLE 1

Sample Demographics (n=40)

Demographic Variable	Frequency (%)
Age	
40–49 years	21 (52.5%)
50–68 years	19 (47.5%)
Race	
White	18 (45%)
African American	18 (45%)
Multi-racial	1 (2.5%)
Declined to answer	3 (7.5%)
Education	
High School	21 (52.5%)
University or Post Graduate	19 (47.5%)
Income	
Under \$30,000	9 (22.5%)
\$30,000-\$59,999	9 (22.5%)
\$60,000+	16 (40%)
Declined to answer	6 (15%)
Health Insurance	
Private Insurance	27 (67.5%)
Medicare/Medicaid	6 (15%)
Uninsured	5 (12.5%)
Missing	2 (5%)
Previous FP Experience	
Yes	16 (40%)
No	7 (17.5%)
Unknown	17 (42.5%)

TABLE 2

Reactions to the FP Experience by Expression of Worry

Subtheme	More Worried	Less Worried	Total Sample (n=40)
Anxiety provoking but necessary	19 (47.5%)	9 (22.5%)	28 (70%)
Encourages healthy behaviors	11 (27.5%)	2 (5%)	13 (32.5%)
Clinician diligence	4 (10%)	4 (10%)	8 (20%)