Information and Involvement Preferences of Women in Their 40s Before Their First Screening Mammogram

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Background: Informed decision making regarding screening mammography is recommended for women in their 40s; however, what information women want and how much involvement in decision making they prefer are not known.

Methods: Surveys were mailed to women aged 40 to 44 scheduled for their first screening mammogram. Women were members of a large New England health maintenance organization and received medical care at a multispecialty practice in the greater Boston area. Outcome measures included information needs and decisional control preferences.

Results: Ninety-six women responded. Of 93 identifying their ethnicity, 62 (67%) were white, 18 (19%) were black, 10 (11%) were Asian, 2 (2%) were Hispanic, and 1 (1%) was other. Most (91% [85/93]) wanted their primary care provider to be the source of information regarding screening mammography. Information needs included the next steps to take if the mammogram result was abnormal (89%), how the woman would be contacted (75%), and how quickly (71%). Women also wanted to know about the harms of false-positive (84%) and false-negative (82%) results, benefits of screening in prolonging life (73%), and risk of getting breast cancer (69%). Most women preferred to make the screening decision after considering their medical provider’s opinion (38%) or together with their medical provider (46%); fewer than 10% preferred that the decision be made by the woman or her provider alone.

Conclusions: Women cited specific information needs before initiating screening mammography, including screening logistics and potential harms and benefits of screening. They also wanted to participate in the decision-making process. Effective methods should be developed for communicating desired information before screening.

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While most groups recommend routine screening mammography for women starting at age 40, they also encourage primary care providers to inform women about the benefits and potential harms of the procedure and to engage the women in shared decision making. However, the literature suggests that women often overestimate their risk of breast cancer and the benefits of screening and are not aware of the possible harms. In addition, little is known about whether and to what extent women wish to be involved in decision making regarding initiating screening. We conducted a survey to determine what information women wanted before initiating screening and what are their preferences for involvement in the decision-making process.

Methods

STUDY SETTING AND PARTICIPANTS

We surveyed women aged 40 to 44 who were members of Harvard Pilgrim Health Care, a large New England health maintenance organization, and who received care at Harvard Vanguard Medical Associates (HVMA), a 14-site multispecialty clinical group practice in the greater Boston area, serving approximately 300,000 patients. Women were identified before their first screening mammogram scheduled at one of the HVMA radiology sites. During the study period, the health maintenance organization insured approximately 60% of HVMA patients; the health maintenance organization has a long history of offering quality cancer prevention services to its membership (totaling approximately 800,000).

The study sample was identified using an automated radiology appointment system at HVMA. We excluded women with a mammography
gram, breast cancer, or breast surgery in the prior 5 years and those without a primary care visit within 1 year of the mammogram appointment. As an incentive to participate, a $2 donation to a breast cancer organization of the woman’s choice was made for every completed survey. The human subjects committees of Harvard Pilgrim Health Care and HVMA approved the study.

**MEASURES**

To determine the women’s information needs about screening mammography, participants were asked to rate the importance on a 5-point Likert scale (1, not at all important; to 5, extremely important) of having 10 specific elements of information before undergoing screening. Examples of information items included “your chances of getting breast cancer in the next 10 years,” “the chances that your mammogram may not find cancer that is actually there,” and “whether there is pain or discomfort involved in getting a mammogram.” The items were based on prior qualitative work in this area.9 The scale performed reliably (α = .87).

Preferences for involvement in the decision-making process were measured using a modified decisional control preferences scale.10 This 5-item instrument asked women to identify their preferences for involvement in decision making regarding screening mammography. Responses included preferring the screening decision to be made by the woman alone, by the woman after considering her medical provider’s opinion, together with her provider, and by the medical provider alone. The last option was whether she preferred to have the medical provider make all medical decisions.

We measured patient demographic characteristics, including breast cancer risk factors. We also measured provider characteristics, such as age, specialty, sex, and length of the patient-provider relationship.

**DATA COLLECTION**

During 16 months, on a biweekly basis, we sent surveys to all potentially eligible women 2 to 4 weeks before their scheduled mammography appointment. A reminder letter was sent 1 to 2 weeks after the initial mailing. Given the temporal nature of the eligibility criteria (ie, women who had already undergone screening were not eligible for participation), no additional contact was made if surveys were not returned following the reminder. Responses were entered into a database by the research team, and all were verified for accuracy.

**STATISTICAL ANALYSIS**

We used descriptive statistics for all outcome measures. We categorized and analyzed the independent variables, such as patient characteristics as shown in Table 1. All analyses were conducted using SAS software, version 8.2 (SAS Institute, Cary, NC).

**RESULTS**

**STUDY PARTICIPANTS**

Surveys were sent to 291 potentially eligible women identified using our automated radiology systems. Among the 144 who responded, 96 were included in the analysis, 7 returned blank surveys or declined participation, and 41 declared they were not eligible for participation because they had had prior mammograms (that were not captured by our automated radiology record data). Due to the high rate of ineligibility (41/144 or 28%), we manually searched the computerized radiology records of a random 30% sample (n = 44) of the 147 nonrespondents and found that 11 (25%) were also ineligible because of prior mammograms, mostly done at outside facilities. Based on the 25% to 30% noneligibility rates, we estimate that 40 of the 147 nonrespondents were ineligible. This leads to an overall response rate of 47% (n = 96) among 203 eligible women. Respondents and nonrespondents were similar in age (mean age, 41.0 and 41.3 years, respectively), time since their primary care appointment (mean, 135 and 133 days, respectively), and clinical center, a surrogate for area of residence and likely socioeconomic status (data not shown).

Most study participants were white, had an annual income of at least $40,000, and had some college education (Table 1). Four participants had a family history of breast cancer, and most had used oral contraceptives. The mammograms were ordered by 55 primary care providers, mostly physicians (n = 37 or 67%), internists (n = 35 or 64%), and women (n = 46 or 84%). The length of the patient-provider relationships was variable, with 22 (23%) of 94 women reporting less than 1 year, 34 (36%) reporting 1 to 5 years, and 38 (40%) reporting more than 5 years. Most women reported 1 visit with the provider per year.

**INFORMATION NEEDS**

Most women (91%) preferred their primary care provider to be the source of information regarding screening mammography. As seen in Table 2, women were particularly interested in the logistical information before their first mammogram, such as which steps to take following an abnormal mammogram (89%), how they will be contacted (75%), and how quickly (71%). They were also interested in information about the harms of screen-
ever, to our knowledge, what information women want acknowledging, such as chances of false-positive (84%) and false-negative (82%) mammogram results. Being informed about the benefits of screening and about breast cancer risk was also important (73% and 69%, respectively). Pain and cost were least-desired information items.

**PREFERENCES FOR INVOLVEMENT**

When asked about their preferences for involvement in screening decisions, 7 (8%) preferred that the decision be made by the woman herself, 35 (38%) preferred that the decision be made by the woman after considering her medical provider’s opinion, 43 (46%) preferred that the woman and her medical provider share the decision, and 8 (9%) preferred that the medical provider make the screening decision. None preferred the provider to make all medical decisions.

**Table 2. Women’s Information Needs Before Their First Screening Mammogram**

<table>
<thead>
<tr>
<th>Information Need</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Logistical</strong></td>
<td></td>
</tr>
<tr>
<td>What are the next steps if the mammogram shows an abnormality?</td>
<td>84 (89)</td>
</tr>
<tr>
<td>How the patient will be contacted about the results of the mammogram</td>
<td>70 (75)</td>
</tr>
<tr>
<td>How quickly the patient will be contacted about the results of the mammogram</td>
<td>66 (71)</td>
</tr>
<tr>
<td><strong>Harms</strong></td>
<td></td>
</tr>
<tr>
<td>Chances that the mammogram may be abnormal but that the patient does not have breast cancer</td>
<td>78 (84)</td>
</tr>
<tr>
<td>Chances that the mammogram may not find cancer that is actually there</td>
<td>76 (82)</td>
</tr>
<tr>
<td>Whether there is pain or discomfort involved in getting a mammogram</td>
<td>54 (57)</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td></td>
</tr>
<tr>
<td>The chances that the patient’s life will be prolonged by getting a mammogram</td>
<td>68 (73)</td>
</tr>
<tr>
<td>Breast cancer risk</td>
<td></td>
</tr>
<tr>
<td>Chances of getting breast cancer over patient’s lifetime</td>
<td>64 (69)</td>
</tr>
<tr>
<td>Chances of getting breast cancer in the next 10 years</td>
<td>63 (68)</td>
</tr>
<tr>
<td><strong>Costs</strong></td>
<td></td>
</tr>
<tr>
<td>Whether the insurance plan will pay for the mammogram</td>
<td>59 (63)</td>
</tr>
</tbody>
</table>

*Denominator varies because of missing data.

While screening mammography for women in their 40s has been debated for decades, most national guidelines recommend routine screening for women in this age group but emphasize that women should be informed about its benefits and harms and engage in informed decision making. For women younger than 50, informed decision making regarding screening mammography is considered especially important because the risk for breast cancer is low, the benefits of screening appear to be slow, and the adverse effects are potentially significant. However, to our knowledge, what information women want before initiating screening mammography has not been previously published; preferences for involvement in decision making regarding screening have only been addressed in a Swiss study of women aged 50 to 69. Our findings suggest that women have information needs about screening that include the logistics of follow-up, the chances of having false-positive and false-negative results, and their risk of breast cancer. Most also wanted to participate in the decision making regarding initiating screening.

We found that having the logistical information, such as what are the next steps to take if the mammogram result is abnormal, how they will be contacted, and how quickly, was important to most women. There has been little emphasis on this type of information in the medical literature, although such information was included in a mammography clinical practice guideline developed by the Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research). Whether the logistical information is best provided by the mammography technicians at the time of the procedure or by the primary care provider is unclear. If the former, primary care clinicians may be able to provide some anticipatory guidance. Online resources are available.

Women were also interested in the harms of mammography, such as the chances of false-positive and false-negative results. A study in community-based mammography settings showed that, although the rate of false-positive results was low for a single mammogram (6.5%), the cumulative rate of experiencing at least 1 false-positive mammogram result during 10 years was 50% for a woman undergoing annual screening beginning at age 40. Although women value receiving information about the likelihood of false-positive results before screening, their anxiety following a false-positive result may not be reduced.

Finally, we found that women wanted information about the risk of breast cancer. The overestimation of breast cancer risk has been documented; therefore, estimating women’s actual risk and counseling them accordingly are needed.

We did not specifically ask about the importance of knowing about ductal carcinoma in situ before screening. It is estimated that more than 55,700 cases of ductal carcinoma in situ are diagnosed in the United States annually, a dramatic increase following the implementation of screening mammography. We (L.N., unpublished data, January 6, 2004) and others have found that most women undergoing screening are unaware of ductal carcinoma in situ; therefore, the possibility of being diagnosed with this disease is an additional issue that should be addressed.

Guidelines have placed a responsibility on primary care providers to engage women in informed decision making regarding screening mammography. Our study further strengthens this need from the perspective of the patients, who want to know their breast cancer risk and be advised about the benefits and potential harms of screening. However, because of lack of time or training, many providers are not equipped to provide this information and need further guidance. Risk assessment and communication tools...
have the potential to assist medical providers, yet most have been developed for research purposes. Several clinically applicable risk assessment tools and decision aids that provide women with information about screening and incorporate patient values are available online. Such tools may be helpful to providers and their patients before or during a discussion about screening; clinical office staff may assist in this process.

To our knowledge, none of the existing tools provide information on the newer potential screening technologies, such as ultrasonography and magnetic resonance imaging, although the emergence of such technologies as new science about the most appropriate interval for screening and genetic markers makes it even more important that providers are equipped to communicate information to women.

Finally, we found that most women wanted an active or collaborative involvement in decisions regarding screening. This finding is consistent with a recent Swiss study that surveyed women aged 50 to 69 and reinforced the need to better equip clinicians to provide women with information and engage them in the decision-making process.

Our study has limitations. First, the response rate of 47% was low, and respondents may have differed from nonrespondents. Because our intention was to survey women immediately before their first mammogram, there was a short time frame in which to respond to the survey. We did not contact the nonrespondents beyond the reminder letter, as the additional delay would have led to a response following the mammogram, thus potentially altering the woman’s information needs and preferences for involvement. In assessing the differences among the respondents and nonrespondents, we found the 2 groups similar by age, time since their primary care appointment, and clinical center. In addition, we found that many nonrespondents already had had a mammogram. Others may have postponed their appointments.

Even so, it is possible that nonrespondents may have had lesser or greater information needs than respondents. To address this possibility, we conducted a worst case/best case analysis using 1 SD from the mean percentage of women who indicated an item to be important. For example, the item most respondents thought important (mean ± SD, 89% ± 31%) was “What are the next steps if the mammogram shows an abnormality?” Assuming the mean response of nonrespondents was 1 SD higher or lower, 72% to 96% of the entire group would have thought the item important. Likewise, for the least important item among respondents (mean ± SD, 57% ± 50%), “Whether there is pain or discomfort involved in getting a mammogram,” the worst-case and best-case range is 30% to 79%. These results suggest that the effect of the nonrespondents would not significantly alter the overall rating of importance of these information items. Given the similarities between the respondents and nonrespondents, we believe that a more drastic difference in responses would be unlikely.

Finally, although our patient population had high representation of nonwhite women, the distribution of incomes was similar to the Massachusetts 2000 census data. Therefore, we believe that our study is generalizable to women in other clinical settings.

Women have specific information needs before initiating screening mammography, including the logistics, harms, and benefits, and prefer to participate in the decision-making process. Effective methods for communicating desired information and involving women in the decision-making process should be developed. It needs to be determined when the information should be provided and by whom.

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