

WHY WOMEN DON'T COME IN FOR BREAST CANCER SCREENING: Results of a Survey of Kaiser Permanente Members Very Overdue for Mammograms

Report prepared by
Nancy P. Gordon, ScD¹
Division of Research
December 3, 2009

BACKGROUND

In January 2009, a report was presented to the Kaiser Permanente Breast Cancer Screening Work Group summarizing findings of a Division of Research (DOR) – Quality Operations Support (QOS) study that examined whether demographic or other factors were associated with breast cancer screening compliance in the year-end 2007 Breast Cancer Screening HEDIS-eligible population. The report compared women who were screening compliant with those who were gently (<1 year) overdue, moderately (1-2 years) overdue, and severely overdue (no mammogram in KP for at least 4 years). Demographic factors included age, race/ethnicity, and English language proficiency. Other factors included length of enrollment, test co-pay, outpatient utilization (any, primary care) during the previous 2 years, PCP type(s), and compliance with other cancer screening tests. Subsequent analyses examined BMI as a predictor of breast cancer screening compliance and being severely overdue.

The major findings of the data-only studies were that there were no apparent race/ethnic differences in breast cancer screening and that co-pay did not appear to be a factor in non-compliance, but that in contrast to cervical cancer screening, compliance increased with age across all race/ethnic groups. Across all age groups, White, Black, and Latina women with a BMI ≥ 40 had significantly lower compliance rates compared to women in the normal to obese (BMI between 18.5-30) range, but the impact of being a very large woman affected compliance with breast cancer screening much less than was observed for cervical cancer screening.

To explore reasons why approximately 15% of women aged 42-64 are very overdue for mammograms (no mammogram at KP for at least 4 years of continuous membership) despite outreach efforts, DOR and the Breast Cancer Screening Improvement Working Group collaborated on a survey of current female KP members aged 46-60 who had been KP members for at least 4 years and had no record of a mammogram during the interval August 2005-August 2009. The specific aims of the survey were to:

- Identify the reasons why these women are not coming in for a mammogram, and
- Identify potential changes in KP breast cancer screening education and service delivery that might increase these women's compliance with breast cancer screening recommendations.

¹ Other DOR staff who helped conduct this survey included Paula Silver, Alice Ansfield, Pete Bogdanos, and Teresa Lin. Edward Huang and Kim Walker provided coordination of QOS efforts and Betty Jue from QOS identified women eligible to be in the study population. Drs. Tracy Flanagan and Nancy Goler reviewed and commented on the survey materials. This survey was reviewed by the KPNC IRB and determined to be non-health services research that can be presented and published outside of KP. The study was funded by KPNC's Community Benefits Program in support of KPNC research to identify disparities in health and health care and explore ways to improve health care delivery.

METHODS

Study Sample

A sample of 500 women was randomly selected from among those who met the following eligibility criteria:

- Age 44-64
- HEDIS-eligible (including no known bilateral mastectomy)
- Continuous KP member for at least 4 years prior to the survey
- At least one visit to any KPNC medical dept between May 2007 and April 2009 and at least one KPNC outpatient visit May 2008-April 2009
- Race/ethnicity data available from clinical/administrative and research sources
- BMI in the past 12 months available from clinical/administrative and research sources
- Not limited in English proficiency
- No record of a mammogram at KP for at least the past 4 years

After an initial random sample of 400 was chosen, additional women were randomly selected from a subgroup of low utilizers (women who had no more than 2 visits May 2007-Apr 2009 with a maximum of one visit during the second year) and a subgroup of women with BMI \geq 40 so that the final sample of 500 included 150 low utilizers and 100 women with BMI \geq 40. To accommodate this oversampling, the initial sample of 400 was reduced dropping in reverse order of selection based on random number assignment.

Questionnaire description

A questionnaire was created based on review of the research literature, feedback from Ob/Gyn clinicians and Regional Health Education staff, and pre-test responses. Women who reported no bilateral mastectomy and no outside mammogram within the past 2 years were asked to indicate from a checklist all the reasons why they had not been getting mammograms as frequently as was recommended. These reasons included logistical reasons (e.g., being too busy/lack of urgency, cost, transportation); perception that a mammogram wasn't needed (e.g., perception that they had a low breast cancer risk, not knowing the recommendations for mammogram frequency or age to start, losing track of how long it had been since last mammogram); concerns about the experience of having a mammogram (e.g., embarrassment, pain and discomfort, radiation exposure, past bad experiences); and concerns related to large body-size (e.g., gowns that don't fit, not wanting to be weighed or lectured about being overweight when they came in, perceptions that technicians and clinic staff are disrespectful of them because of their weight). Women were also given the opportunity to write in other reasons. Following this checklist of reasons was another checklist of things KP could do to encourage them to come in to KP for a mammogram. Potential actions KP could take included making appointments more convenient (e.g., same day, walk-in, weekday evenings, Saturdays), guaranteeing a female technician to do the Pap test, reducing the cost, providing gowns that fit better, and training staff to be more respectful and welcoming. Women were also able to write in other suggestions or comments.

Survey mailing

Surveys were mailed at the end of August 2009, with a follow-up mailing approximately three weeks later to nonrespondents. Survey mailings consisted of a questionnaire, a cover letter and a stamped, pre-addressed envelope for returning the questionnaire. To encourage response, participants were offered a \$5 Target or Safeway gift card upon return of a completed questionnaire or completion of the questionnaire via phone interview. Since by mid-October only 131 women had responded to the mailed survey, we decided to complete additional phone

interviews with respondents so as to accrue data for 50 women in the BMI ≥ 40 subgroup and information on at least 20 women who had not responded to the mailing.

Response Rate

Altogether, surveys were sent to 500 women and information was obtained from 188 (37.6%). Of the remaining 320 in the sample, a total of 46 were unreachable (n=18), no longer a KP member (n=19), deceased (n=1), or having had a mammogram between the 1st and 2nd mailings (n=8). Using the denominator excluding these 46, our response rate is 41.4%.

Characteristics of Final Respondent Sample (n=188 overall, n=169 providing reasons)

Respondents ranged in age from 46 to 60, with a median age of 54 and race/ethnic breakdown of 63.8% nonHispanic White, 11.7% Black, 10.6% Latina, 12.2% Asian, and 1.6% Native American. Approximately 30% had a BMI ≥ 40 and 27% were considered low utilizers of KP outpatient services during the 2 years prior to the survey². The age and race-ethnicity composition of the subsample of 169 women who provided reasons for not coming in were virtually the same, and included 50 women with a BMI ≥ 40 and 46 low-utilizers. Approximately 2/3 were listed in the PMT database as “Never Had a Mammogram” and the others “Very Overdue.”

FINDINGS

Information relevant to eligibility to be in the Mammogram outreach not in KP records: Of the 188 women who responded, 6 (3.2%) reported having had a bilateral mastectomy. Thirteen (6.9%) women reported having had a mammogram outside of KP during the previous 2 years, and 8 of these 13 women planned to continue going to an outside provider for mammograms. These 19 women did not answer the questions about reasons for not having a mammogram.

Mammogram history: Of the 124 respondents who were listed in the PMT as never having had a mammogram, 29 (23.4%) said that they'd had a mammogram in the past, including the 13 who reported having had their last mammogram outside KP. Thus, it would be more accurate to label the category as “NEVER MAM AT KP,” making no assumptions that all these women have never had a mammogram.

Reasons indicated for not coming in for a mammogram: In addition to analyzing our data for all 169 women who provided reasons, we also separately analyzed the data for respondents with no history of having had a mammogram in the past (based on outreach categorization validated by self-report), no history of having a mammogram in KPNC (> 4 yrs ago vs. Never, based on outreach categorization), and by BMI (≥ 40 vs. < 40) to determine whether size-related barriers matter as much for mammogram compliance as they appear to for Pap test compliance.

Table 1 shows the overall percentages of women who indicated each different reason for not coming in for a mammogram. Since women were told to indicate as many reasons as apply, the summed percentages exceed 100%. Highlights of the findings are bulleted below.

- The most frequently cited reasons for not having come in for a mammogram (aside from just not wanting to have a mammogram) were related to the discomfort of the procedure (some called it barbaric) either experienced personally or heard about, concerns about the annual low dose radiation exposure, and perception that risk for developing breast cancer was low (no family history of breast cancer or just perception of low risk) so no mammogram was necessary without symptoms indicating a problem. These were the

² Made 1 outpatient visit to any KP department during the previous 12 months and no more than 2 outpatient visits during the previous 24 months.

most frequently cited reasons by the whole group (**Table 1**), by women who had never had a mammogram (**Table 2**), and by women who said they didn't want to come in for a mammogram even if KP made changes to make getting them more convenient (**Table 3**).

- Women who were very overdue for mammograms were more adamant about not wanting to have the procedure than very overdue women were for Pap tests.
- Having a breast implant was an unexpected barrier that needs to be further explored since 8 of the 169 women hadn't had a mammogram because of concerns that their breast implants might be damaged or that the mammogram wouldn't be effective because of the breast implants. Most of these women wanted to find an alternative screening procedure that wouldn't put so much pressure on the breasts, or wanted KP to assume responsibility for fixing any damage caused by the mammogram.
- Only 6 women said that they didn't think a mammogram was needed at their age, and 5 of these were aged ≤ 50 yr.
- Reasons cited by very large women for not coming in for a mammogram supported the interpretation of the mammography compliance study results that being a very large woman isn't as much of a barrier for getting a mammogram as it is for getting a Pap test (**Table 4**). While very large women were more likely than those with BMI <40 to cite the size of gowns, not wanting to be weighed or lectured about weight or body size, and staff disrespect as factors for not coming in, and were also more likely to request gowns that fit better and better staff training as a way to get them to come in, the most frequently cited reason for not having a mammogram was the discomfort of the procedure.

Changes related to service delivery that might motivate very overdue women to come in for a mammogram are shown in **Table 5**: Fewer women indicated potential changes KP could make in service delivery than had indicated reasons. Based on data from 53 women whose responses suggested they might be willing to come into KP for a mammogram (8 others wanted to continue getting them with their outside provider), it would appear that making the mammogram appointments available during some evening and Saturday hours would likely increase the numbers of very overdue women coming in for a mammogram. Guaranteeing that the mammogram will be done by a female technician might also make more women more comfortable with the idea of the procedure. Publicizing the fact that women aren't weighed and counseled during the mammogram appointment and having large capes available that can fit a wide range of sizes might cut down on resistance to the mammogram by large women. However, the fact that nearly 40% of women who were very overdue for a mammogram indicated that there was nothing that KP could do that would encourage them to come in for a mammogram because they just didn't want one suggests that these service delivery changes will not reduce the main barriers to women coming in. Those barriers -- the perception that the procedure is very uncomfortable and even painful, that it might be dangerous (due to the accumulated radiation exposure over several years), and that they are at low risk for breast cancer so the need to subject themselves to the discomfort and radiation isn't warranted, especially for women under the age of 50 -- will need to be addressed through outreach education and encouragement from trusted sources.

CONCLUSIONS

This survey found that while several women are likely getting mammograms outside the KP system, the majority of women who are very overdue for a mammogram know that they are overdue, and many have never had one. Unfortunately, there are probably more barriers to getting women to come in for a mammogram than for a Pap test. A sizeable proportion of women who have put off getting a mammogram consider their breast cancer risk to be low enough not to subject themselves to the discomfort of the procedure and potential iatrogenic effect of the cumulative exposure to low dose of radiation. Comments made by U.S. Preventive Services Task Force members suggesting that screening mammography is not as effective and

targeted as it needs to be and at younger ages may be doing more harm than good will likely make reluctant women of all ages even more reluctant to have the procedure. Many of the women who have been putting off having mammograms expressed interest in learning about alternative methods of breast cancer screening, including digital mammography, sonograms, thermography, and MRIs, mostly with the hope of avoiding breast discomfort during the procedure as opposed to increasing screening effectiveness.

The fact that discomfort is such a major barrier suggests that it is important to provide information about how to minimize the pain of a mammogram and making it easy for a woman to act on that information. For example, pre-menopausal women could be instructed to schedule their appointment at a time of the menstrual cycle when the breasts aren't more sensitive than usual, but this only helps if appointment slots are available at short notice. Additionally, technicians can be trained to make them more overtly sympathetic to women coming in scared of the procedure and expecting it to be very painful, more gentle and respectful in the way they manipulate women's breasts in the machines, more talkative through the procedure so that the women know what is going to happen, and more responsive so that women have a sense of control and can stop the procedure for a moment if they become too uncomfortable.

Finally, while cost was a major barrier to getting a mammogram for only a small percentage of these very overdue women, and the number of women in this situation may be increasing as co-pays for preventive care increase and the number of women with deductible plans increases. Because many women who have not recently had a mammogram probably are unaware of what it will cost them, this is a factor that should be monitored over time.

Table 1. Reasons indicated for not coming in for a Mammogram (n=169)

Logistics and cost		Concerns about the mammogram	%
Didn't know how to schedule appt	1.8 %	Concerned about the annual low dose of radiation from the test	26.6 %
Thought MD referral needed	3.0 %	Afraid her breasts could be bruised	7.7 %
Too embarrassed to come in because so overdue	12.4 %	Afraid mammogram will damage her breast implants/not be accurate with implants	4.7 %
Hard to come in during weekday hours for non-urgent appts.	8.9 %	Feels embarrassed being undressed in front of a technician (even female)	8.9 %
Life is too busy to come in for this screening test or didn't consider this an urgent procedure	18.3 %	Feels very uncomfortable having a technician (even female) touch her breasts	5.9 %
Hard to get transportation to clinic during weekday hours	3.0 %	Mammogram too uncomfortable or painful	38.5 %
		Heard this secondhand	21.3 %
		Experienced this herself	24.9 %
Costs too much (co-pay too high)	8.3 %	Afraid mammography equipment won't fit her body and it will be too uncomfortable	3.6%
		Had bad experience with a clinician during a mammogram or other hands-on exam	7.7 %
Didn't think a mammogram was needed:		Doesn't think mammograms are effective at detecting breast cancer	4.1%
Lost track of how long ago had it	6.5 %	Has gotten "alternative" to mammogram	2.4 %
Didn't think needed at her age ¹	3.6 %	Doesn't want to find out if has breast cancer	7.1 %
Didn't know mammogram was due every 1-2 yrs	0.6 %	Afraid that procedure may remind her of past molestation/abuse	1.8 %
Didn't think every 1-2 yrs was needed, just recommended	8.3 %	Gowns too small or don't cover up enough	4.7 %
Regular doctor didn't say to get a mammogram	3.0 %	Just doesn't want to get a mammogram no matter what	37.8 %
Low risk → Not necessary No family history of breast cancer Considers self low risk for breast cancer, so doesn't see need if has no "symptoms"	28.4% 26.0% 14.2%	Other reasons related to KP Care	
		Doesn't want to be weighed or lectured about weight or body size when come in	8.9%
		Have had bad experiences with staff who seemed uncomfortable, disrespectful, or negative due to her size	5.9%

¹ 5 of the 6 women who indicated they didn't know they needed a mammogram at their age were aged 50 or under

Table 2. Reasons given by women who have never had a mammogram (n=95)

	%	N
Just doesn't want one	38.9	37
Heard mammograms were very uncomfortable and painful	30.5	29
Concerned about annual low dose radiation exposure	34.7	33
Considers self at low risk for developing breast cancer	28.4	27
Life is too busy/doesn't consider this procedure as urgent to get	21.9	21
Embarrassed to be undressed in front of a technician (even a female)	12.6	12
Embarrassed because knows she's very overdue	12.6	12
Can't come in for non-urgent appts. during weekday hours	10.5	10
Doesn't want to find out if has breast cancer	9.5	9
Cost of the mammogram too high	9.5	9
Doesn't want to be weighed or lectured about weight or size when comes in	8.4	8
Thought mammogram was recommended every 1-2 yrs, not needed	7.4	7
Doubts effectiveness of mammography	5.2	5
Concerned about mammogram with breast implants	5.2	5

Table 3. Reasons given by women who said they didn't want to come in for a mammogram (n=64)¹

	%	N
Believes based on personal or secondhand experience that mammograms are very uncomfortable and painful	51.6	33
Concerned about annual low dose radiation exposure	37.5	24
Considers self at low risk for developing breast cancer and has no "symptoms" to suggest breast cancer	31.3	20
Doesn't want to find out if has breast cancer	9.4	6
Cost of the mammogram too high	7.8	5
Doubts effectiveness of mammography	7.8	6
Concerned about mammogram with breast implants	4.7	3
Doesn't want to be weighed or lectured about weight or size when comes in	3.1	2

¹ Additionally, some of these women said they'd come in if they could be screened using a different procedure.

Table 4. Differences in selected response options between women with BMI <40 and BMI ≥40

Reasons for Not Having Had a Mammogram in at Least 4 Yrs	BMI <40 (n=119)	BMI ≥40 (n=50)
Believes based on personal or secondhand experience that mammograms are very uncomfortable and painful	34.4%	48.0%
Feels embarrassed being undressed in front of a technician (even female)	9.2 %	8.0 %
Feels very uncomfortable having a technician (even female) touch her breasts	5.0 %	8.0 %
Had a bad experience with a clinician during a mammogram or other hands-on exam	7.6 %	8.0 %
Gowns too small or don't cover enough	0	16.0% **
Afraid mammography equipment won't fit her body and it will be too uncomfortable	2.5 %	6.0 %
Has had bad experiences with staff who seemed uncomfortable, disrespectful, or negative due to her size	2.5 %	14.0 % **
Doesn't want to be weighed or lectured about weight or body size when comes in	2.5 %	24.0 % ***
Embarrassed because knows is overdue	10.1 %	18.0 %
Concerned about radiation	32.8 % **	12.0 %
Considers self to be low risk (no family history, other reasons, not symptomatic)	31.1 %	22.0 %
Too busy/low priority to come in for a mammogram	14.3 %	28.0 %
Just doesn't want a mammogram	44.5 % **	22.0 %
Changes that might encourage women to come in for a mammogram		
Gowns that fit better	1 / 89	8 / 33 ***
Train staff to be more respectful and welcoming	4 / 89	7 / 33 **

* p<=.05; ** p<.01; *** p<.001

Table 5. Changes that might motivate women to come into KP for a mammogram (restricted to n=53 women who seemed open to coming in)¹

Guarantee a female technician will do the mammogram	42.2% (22)
Offer weekday evening appointments	28.3% (15)
Offer Saturday appointments	22.6% (12)
Schedule mammogram at a time when will already be at KP	20.8% (11)
Offer same day or next day appointments	13.3% (7)
Call her to schedule an appt and then remind her a few days before	17.0% (9)
Reduce cost (co-pay) for the test	20.7% (11)
Train technicians/clinic staff to be more respectful and welcoming	20.7% (11)
Provide gowns that fit better	20.7% (11)
Tell woman in advance that she won't be weighted or lectured about her weight when she comes in ²	24.5% (13)

¹ Excludes women who reported having a bilateral mastectomy, who wanted to continue getting mammograms from a non-KP provider, and who just don't want to get a mammogram)

² Inferred from response to reasons for not coming in.

IMPROVING KAISER PERMANENTE BREAST CANCER SCREENING SERVICES (MAMMOGRAM)

Your medical record shows that you have not had a mammogram at Kaiser Permanente in the past 4 years. We want to learn why some women aren't coming in for mammograms and if there are things we can do to help more women get this important cancer screening procedure. Your responses are important to us. **Please fill out this questionnaire and we will thank you with a \$5 gift card.** Your answers are confidential. They will not go into your medical record nor be shared outside the Division of Research in a way that can identify you.

1. Have you had a bilateral mastectomy (both breasts surgically removed)?

- No → Continue with Question 2
- Yes → *Please skip to the end of the questionnaire to choose your gift card*

2. Have you had a mammogram in the past 4 years?

- No → Continue with Question 3
- I've never had a mammogram → Continue with Question 3
- I don't know → Continue with Question 3
- Yes, I had a mammogram **outside of Kaiser Permanente**
→ *If YES, please answer Questions 2a and 2b below:*

2a. Where do you plan to get your next mammogram?

- At Kaiser Permanente
- At a non-Kaiser Permanente office or clinic

2b. When did you have your last mammogram?

- Less than 1 year ago
- 1-2 years ago
- Over 2 years ago

*If you think you had your last mammogram over 2 years ago, continue with Question 3.
If you had one less than 2 years ago, skip to Question 4.*

3. Women have different reasons for not getting mammograms as frequently as recommended.

Please mark the box next to each reason that describes your situation. The list continues on the next page, and there is space at the end to write in other reasons. (Check **ALL** that apply)

I have problems with scheduling, cost, or transportation:

- I wasn't sure how to schedule an appointment for a mammogram
- I thought I needed a doctor referral to get a mammogram
- I feel embarrassed about coming in because I know I'm overdue
- It's hard for me to come during a week day for a non-urgent appointment
- My life is just too busy to come in for this screening test
- I can't or don't want to spend money to get a mammogram
- It's hard for me to get transportation to the clinic during weekday hours

I didn't think I needed a mammogram because:

- I didn't realize it had been that long since I had my last mammogram
- I didn't know I needed a mammogram at my age
- I didn't know I needed a mammogram every 1-2 years
- I didn't think having a mammogram every 1-2 years was necessary, only recommended
- My regular doctor didn't tell me I needed to get a mammogram
- I had a partial mastectomy and thought a mammogram was no longer needed
- I don't have any family history of breast cancer
- I think I have a low risk of getting breast cancer so I don't think I need a mammogram

Please continue on other side ►►►

I have concerns about the mammogram:

- I've heard that a mammogram can be uncomfortable or even painful
- I'm afraid my breasts could be bruised
- I feel embarrassed being undressed in front of a technician, even a female technician
- I feel very uncomfortable having a technician touch my breasts, even a female technician
- It's too uncomfortable standing up for the procedure
- My last mammogram was very uncomfortable
- I'm concerned about the effect on my body of having low dose radiation year after year
- I've had a bad experience with a clinician during a mammogram or other hands-on exam
- Paper or cloth gowns are too small for me or don't cover me enough
- I'm afraid that the mammography equipment won't fit my body and it will be too uncomfortable

I have other reasons for not wanting to have a mammogram:

- I've had bad experiences with staff who seemed uncomfortable, disrespectful, or negative toward me due to my size
- I don't want to be weighed or lectured to about my weight or body size
- I don't want to find out if I have breast cancer
- I'm afraid that this procedure may remind me of a past experience of being molested or abused
- Other (please describe): _____

If you marked more than one reason for not having a mammogram, please put a star (*) to the left of the box of your *main 1 or 2 reasons*.

4. Is there anything Kaiser Permanente could do to encourage you to come in for a mammogram within the next 2 months? (Check **ALL that apply and list others)**

- No, I prefer to continue to get my mammograms outside of Kaiser Permanente
- No, I just don't want to have a mammogram
- Have same-day or next-day mammogram appointments available
- Schedule it at a time when I will already be at Kaiser Permanente for other appointments
- Offer Saturday mammogram appointments
- Offer weekday evening mammogram appointments
- Call me to schedule an appointment; remind me a few days before and the night before
- Guarantee that a female technician will do my mammogram
- Provide gowns that fit my body better
- Train technicians and clinic staff to be more respectful and welcoming
- Reduce my cost for the mammogram
- Cover my transportation costs
- Other: _____

If you marked more than one thing that would encourage you to come in for a mammogram, please put a star (*) to the left of the box of the *most important thing* we could do.

Study ID: _____