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Language Barriers, Location of Care and Delays in Follow-up of Abnormal Mammograms

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Abstract

Background—Breast cancer is frequently diagnosed after an abnormal mammography result. Language barriers can complicate communication of those results.

Objectives—We evaluated the association of non-English language with delay in follow-up. Methods: Retrospective cohort study of women at three mammography facilities participating in the San Francisco Mammography Registry (SFMR) with an abnormal mammogram result from 1997-2008. We measured median time from report of abnormal result to first follow-up test.

Results—Of 13,014 women with 16,109 abnormal mammograms, 4,027 (31%) had a non-English patient language. Clinical facilities differed in proportion of non-English-speakers and in time to first follow-up test: facility A (38%; 25 days), facility B (18%; 14 days), facility C (51%; 41 days). Most (67%) mammography examinations had BIRADS 0 (incomplete) assessment, requiring radiographic follow-up. At 30 days of follow-up 67% of all English speakers with incomplete assessments had a follow-up exam compared with 50% of all non-English speakers ($p < .0001$). The facility with the least delay and the lowest proportion of non-English speakers, had the biggest difference by language; compared to English speakers and adjusting for education, non-English speakers had twice the odds of >30 day delay in follow-up (OR 2.3; 95 CI 1.4-3.9).

Conclusions—There are considerable differences among facilities in delays in diagnostic follow-up of abnormal mammography results. More attention must be paid to understanding mammography facility factors, such as wait time to schedule diagnostic mammography and radiology workload, in order to improve rates of timely follow-up, particularly for those facilities disproportionately serving vulnerable non-English speaking patients.

Background

Communication across languages is a fundamental component to the provision of quality health care for diverse populations. Almost 45 million Americans speak a language other than English at home, and more than 19 million speak English less than very well and are considered of limited English proficiency (LEP).(1) As with English-speakers, many LEP women who undergo mammography will be given an abnormal mammogram result.(2-5)

Because of the high false positive rate of mammography, the majority of abnormal mammograms ultimately turn out to be benign findings.(6, 7) However, a substantial proportion do lead to a cancer diagnosis,(5, 8, 9) and thus all abnormal mammography results require timely follow-up.

Lack of timely follow-up of an abnormal mammogram result can lead to a delay in diagnosis, and in turn diagnosis at a later stage and potentially decreased survival.(10-12) In addition to negatively impacting survival, delays in follow-up care often cause psychological distress, including anxiety and depression.(13-15) Minority women diagnosed with breast cancer have been shown to have longer delays than white women both pre-clinically and once in care.(16-23)

Communication between a woman and her provider about an abnormal mammography result and next steps in care is a fundamentally important part of the follow-up process. Adequate communication can help relieve anxiety,(24) and increase the likelihood of appropriate follow-up.(25-27) Minority women often experience poor communication after an abnormal mammography result, contributing to less knowledge and more anxiety, and creating a barrier to timely follow-up care.(21, 28, 29)

Minority women with limited English proficiency have the additional obstacle of a language barrier; however, it is not known if this additional barrier contributes to delays in follow-up of abnormal mammograms. In this study we set out to answer the following question: is a language-barrier associated with delay in follow-up of an abnormal mammogram?

Methods

Data Sources

Mammography and follow-up data were from the San Francisco Mammography Registry (SFMR). The SFMR, a participant in the National Cancer Institute's Breast Cancer Surveillance Consortium (<http://breastscreening.cancer.gov>), collects data on all women undergoing mammography at radiology facilities in San Francisco and Marin counties.(30) Women are asked to complete a brief questionnaire at the time of their mammogram; if they do not want to participate in the SFMR, they are given the option to opt-out. If they do not opt out, their questionnaire and imaging data, including mammography and ultrasound, are included in a central research database housed at the University of California at San Francisco. When available, biopsy data is also incorporated into the database. The SFMR also annually links women in its registry to the California Cancer Registry to identify women with breast cancer diagnoses. The SFMR adheres to strict confidentiality procedures, complies with the Health Insurance Portability and Accountability Act, and has a Federal Certificate of Confidentiality and other protections of research subjects, radiologists, and mammography facilities.

Language data were drawn from administrative data on patients' language at the individual mammography facilities. We were able to obtain reliable data for patient language at three SFMR facilities, each of which were embedded in a larger hospital system, which collected and recorded patient language. These data were merged with the SFMR data.

Sample Selection

We included all women 30 years and older with an index abnormal screening or diagnostic mammogram from 1997- mid-2008 at any of the three SFMR facilities from which we obtained language data. While their index mammogram had to be at one of these three facilities, their follow-up exam could have been at any SFMR facility. We excluded women younger than 30 because these women are likely to be at very high risk for breast cancer and

their follow-up is also likely to be quite different than for older women. We also excluded women who had a prior history of breast cancer, whether by self-report on the questionnaire or documented in registry data. We further excluded women for whom language data was missing or unknown.

Because there was differential availability of biopsy data at the three facilities, we only included those mammograms with breast imaging and reporting data system (BIRADS) category 4 (suspicious) or 5 (malignant) result during the time-frame in which biopsy information was available. For facility A this was from November 2004 through mid-2008, for facility B this was during the entire timeframe of the study, and for facility C this was from June 2004 through mid-2008. For diagnostic studies with BIRADS 3 (probably benign) assessment and all screening examinations with a BIRADS 3 assessment with a recommendation for immediate follow-up or BIRADS 0 assessment (need additional imaging), data were included for all facilities for all study years.

Mammography Facilities

All three facilities are located within the city of San Francisco. One facility is a community hospital accepting both private and public insurance. While there are breast radiologists at this site, there is not a breast health center. The predominant non-English language of patients seen at this facility is Spanish. While much of the staff also speaks Spanish, this facility does not have a formal interpreter services department.

The second facility is a hospital with a breast health center accepting both private and public insurance. The predominant non-English languages of patients seen at this facility are Chinese, Russian and Spanish. This site does have a formal interpreting services department with in-person professional interpreters available by appointment in the three predominant languages, as well as remote telephonic interpreting.

The third facility is a hospital that added a breast health center in 2004. This hospital serves an indigent and publicly insured population. During the time period of the study the number of mammograms done at this site increased approximately four-fold, without a commensurate increase in radiologist staff. The predominant non-English languages of patients seen at this site are Chinese, Russian, Spanish and Vietnamese. This site does have a formal interpreting services department with in-person professional interpreters available in the four predominant languages, as well as remote telephonic interpreting. Since 2001 this site also has had Spanish speaking, and since 2002 Chinese speaking, patient navigators.

Primary Predictor

Our primary predictor was the woman's language as recorded in the administrative database from the medical center at which she had her index mammogram. Patient language is collected routinely as part of registration for clinical care at the three participating sites. During the time-course of this study none of the sites had a standardized measure to collect language information, but rather used the common practice of allowing registration clerks to assess the patient's language. We included all women who had any documented language and categorized each woman as either English or non-English speaking. The non-English speaking group included all women with a non-English language recorded in the administrative database. While it would be most reliable to directly assess a woman's English proficiency by asking her how well she speaks English,(31) it was not feasible to do this retrospectively for thousands of women. However, in our prior work in this area, we have found that registration language data are surprisingly accurate and misclassification is usually in the direction of classifying non-English speakers as English speakers rather than

the other way around,(32) which suggests that any findings of difference by language will be a conservative estimate.

Primary Outcome

Our primary outcome was time to follow-up exam after the index abnormal mammogram. We stratified our outcome by BIRADS category to account for the fact that the appropriate timing and type of next exam differs by BIRADS category. Thus, for diagnostic BIRADS 3 results (probably benign), the expected appropriate timing and type of follow-up exam is a 6-month short interval follow-up mammography examination; for BIRADS 3+ or 0 it is immediate additional breast imaging, and for BIRADS 4 or 5 results it is immediate additional breast imaging and/or biopsy.(33) For any given woman, we included only the first abnormal mammogram in each BIRADS category within the SFMR; thus, any given woman could have multiple mammograms included in the analysis if those mammograms had different BIRADS results. For example, if a woman had a mammogram result of 0, that mammogram required immediate follow-up mammography. The follow-up mammogram might have a result of 4; that mammogram also required its own immediate follow-up, this time probably a biopsy. Because the outcomes are stratified by BIRADS category, both the BIRADS 0 and the BIRADS 4 mammogram could be included in the analysis. However, if that same woman had another BIRADS 0 mammogram result the next year, it would not be included in the analysis.

Analysis

We used descriptive statistics to describe the women in the sample, including patient language, ethnicity by self-report, age at the first index mammogram, and education by self-report. We further describe the proportion of mammograms in each BIRADS category overall and by clinical facility, as well as the overall median days to first follow-up by clinical facility.

The remainder of our analysis was stratified by BIRADS category. For each BIRADS category (diagnostic 3, 3+/0, and 4/5) we describe the time to follow-up by language group (English vs. non-English). We also describe the proportion that had timely follow-up by group. Chi square was used throughout to test the differences between proportions. For all BIRADS categories, we planned to use survival analysis to compare time to follow-up for the English and non-English groups; however, our data violated the assumption of proportionality required for survival analysis and proportional hazards models. When investigated by site, the curves each cross at different time-periods, indicating departure from proportional hazards and disallowing use of this method. Thus we investigated specific cut-offs which had face validity for quality clinical care. For those BIRADS results requiring immediate follow-up (3+/0 and 4/5), we investigate two different cut-offs for timely follow-up: 30 days and 60 days; for the less urgent BIRADS 3 results requiring 6-month follow-up, we investigate two longer cut-offs: 9 months and 12 months. Lastly we examined the time to follow-up and used logistic regression to model the odds of delay (>30 days to follow-up exam) for BIRADS 3+/0 results by clinical facility. For the models, first we included only our primary predictor, language; followed by inclusion of both language and education.

Finally, we describe the subgroup of women who were diagnosed with breast cancer subsequent to their index mammogram, comparing the timeliness of their follow-up by language group. The Mann-Whitney test was used to compare the medians of follow-up times by the two language groups.

Results

Figure 1 describes the sampling frame, starting with all 329,415 unique women with mammograms in the SFMR during the time-frame of the study 1997 to mid-2008; 24% of these women had a mammogram at one of the three study facilities. At these three facilities, there were 18,110 unique women with an abnormal mammogram during the study time-frame. Of these, 13,014 (71%) were eligible to be included in this study and together they had a total of 16,109 abnormal mammograms. The largest exclusion was due to no language data in the registration databases (18%). Our outcome variable did not differ between this excluded group and the included group of women ($p=0.4$).

Among the included women, a little over a third was non-English speaking. The most common non-English language was Spanish, and next common were Asian Languages and Russian. Among the Asian Language group, 65% were Chinese-speakers. Among the English speakers, half were white, 15% African American, 15% Asian American and 6% Latina. The majority in both language groups were age 40-60 years, with slightly higher proportion of non-English speakers older than 70. Almost half of the English speakers had graduated from college; whereas more than a third of the non-English speakers had not graduated from high school. In both groups, the majority of the index mammograms were BIRADS 0 assessments requiring immediate follow-up imaging. (Table 1)

Both the distribution of language and BIRADS category differed by mammography facility. Half of the women with an index abnormal mammogram at facility C were non-English speakers, compared to a third of women at facility A and only 18% at facility B. All three facilities had a relatively low proportion of examinations with a BIRADS 3 assessment. In contrast, the distribution of BIRADS 4/5 assessments differed considerably; facility B had the most and facility A the least. This was at least in part due to differential inclusion of these mammograms because of differentially complete biopsy data as described in our methods. Notably, the sites also differed in their overall timeliness of follow-up for exams requiring immediate follow-up. The clinical facility with the highest proportion of non-English speakers also had the longest time to follow-up, with a median well over a month; conversely, the facility with the lowest proportion of non-English speakers had the shortest time to follow-up with a median of two-weeks. (Table 2)

Time to Follow-up by BIRADS Category

When grouping all the clinical facilities together, but stratifying by BIRADS category, non-English speakers had longer time to follow-up than English speakers for exams requiring immediate follow-up, particularly for incomplete (3+/0) results. At 30 days of follow-up 67% of English speakers with incomplete results had a follow-up exam compared with 50% of non-English speakers ($p<.0001$). At 60 days, more women in both groups had a follow-up exam and the gap was smaller (83% English vs. 75% non-English; $p<.0001$). The results were similar, although less marked, for BIRADS 4/5 exams (at 30 days: 71% English vs. 63% non-English, $p<.0001$; at 60 days: 85% English vs. 80% non-English, $p=0.001$). For exams requiring short-interval follow-up (diagnostic BIRADS 3), however, non-English speakers had higher rates of timely follow-up than English speakers (at 9 months: 73% English vs. 79% non-English, $p=0.02$; at 12 months 82% English vs. 90% non-English, $p=0.0008$).

Time to Follow-up of Incomplete Exams by Clinical Facility

We examined further the differences by language for incomplete mammogram results as these were the exams for which we had the most robust follow-up data for all facilities. Stratifying by clinical facility revealed that the overall difference by language appears to be

largely driven by facility differences. The facility with the timeliest follow-up overall (facility B) was the site with the biggest difference by language. This is the site with the lowest proportion of non-English speaking patients. Among the main non-English speaking language groups at this facility, compared to English speakers, Russian speakers had the same time to follow-up, whereas Asian-language and Spanish speakers had longer times to follow-up. By contrast, the other two sites with between 30-50% non-English speaking patients had longer times to follow-up, but no substantial difference by language. In fact, the non-English speakers appear to have somewhat shorter follow-up times than English speakers at the facility with the most LEP patients, which is also the facility with bilingual patient navigators. (Figure 2)

Modeling the odds of delay showed the same results, with no difference by language group for facilities A or C, but higher odds of delay in follow-up for incomplete mammogram results for non-English speakers at Site B. Adding education in the models did not change these results. (Table 3) These results were unchanged in sensitivity analyses excluding women under 40 (n=416) and excluding women with a diagnostic index mammogram (n=336).

Time to Follow-up for Women Diagnosed with Cancer

There were 1467 women in our cohort with breast cancer diagnoses in the two years after their index mammogram. Of these, 223 had a BIRADS 3+/0 result, 1,230 had a BIRADS 4/5 result, and 14 had a BIRADS 3 result on their first abnormal exam in our database. Two women had no follow-up documented in our database, both English speakers. The majority of women had follow-up of their index abnormal exam within 30 days; more English speakers than non-English speakers had follow-up within 30 days, this was a statistically significant difference 78% vs. 66%; $p<.0001$). There was a difference in median time to first follow-up, with non-English speakers waiting a week longer for their follow-up (12 days vs. 19 days; $p<.0001$).

Discussion

In this study we investigated the impact of a language barrier on the timeliness of follow-up for an abnormal mammogram result. We found that non-English speakers were more likely to be seen at facilities with longer overall delays in follow-up for all women. At the facility with bilingual patient navigators, non-English speakers had slightly less delay in follow-up than English speakers. In fact, differences by language were most prominent at the facility with the least delays overall and with the lowest proportion of LEP women. At this facility, having a language barrier was associated with a higher probability of delay regardless of education level. However, time to follow-up begins to equalize at this facility within two-months after the index abnormal mammogram. At the other two facilities, all women have lower rates of follow-up than women at the facility with the best follow-up at both one and two-months after the index mammogram, indicating that the differences by site of care overwhelm the differences by language.

Our finding that LEP women at the facility with the least delays did have a disparity in follow-up compared to English speakers is consistent with prior studies by race-ethnicity that found disparities within a single system of care.(17, 18, 23) Others have examined patients across multiple facilities and found disparities in timeliness of follow-up, particularly for African American women compared to whites; however, they have not examined differences by facility as we have done in this study.(19-21) Much of the prior research explores demographic, health, psychosocial and logistical/social support factors, which might contribute to delay.(34) While these patient factors are clearly important, our finding that some mammography facilities have much lower rates of delay in follow-up than

others, implies that focusing on patient factors alone likely will be insufficient to improve timely follow-up, particularly for vulnerable populations. It is important to investigate the contribution of radiologist workload as well as tracking and scheduling systems to disparities in follow-up between facilities.

Several studies have highlighted the importance of good verbal communication between women and their physicians about their abnormal mammography results.(25-27, 29) Traditionally, the expectation is that communication will be initiated by the physician that requested the screening examination; mammography facilities are required only to send a letter in English to the women within 30 days of the examination.(35) Yet, outpatient primary care physicians are under increasing time-pressures,(36-40) and timely communication about abnormal results may not be achieved in a consistent fashion by all physicians for all women. Thus, systematic approaches to improving verbal communication between mammography facilities and patients may be more achievable.

Interventions to decrease delays in diagnosis after an abnormal mammogram have largely focused on patient navigators.(28, 41-43) While participants in these studies have ranged from women with a breast abnormality (clinical or radiologic) to only women with a BIRADS 4 or 5 mammogram result, they have in common a focus on minority women, and an intensive navigator intervention which includes tracking, follow-up phone calls, and sometimes transportation and mental health counseling. Two of these studies included non-English speakers.(28, 41) The studies differ in their definition of timely follow-up from diagnostic resolution within 60 days(43) to within 8 months(28). Nonetheless, whichever the definition of timeliness, it does appear that patient navigation is an improvement over no navigation. In fact, bilingual patient navigators may have been a contributing factor to why non-English speakers fair even better than English speakers at the facility in our study which utilizes navigators. It remains unclear, however, if there is any one component of patient navigation which is most effective for the majority of patients. While patient navigation may well be an important part of any medical center's efforts to achieve timely breast cancer diagnoses for its most vulnerable patients, for those medical centers which disproportionately serve vulnerable populations, including non-English speakers, an in-depth high resource patient navigation program may need to be reserved for only a small proportion of the population. This was the case for our facility with the longest delays to diagnostic follow-up. That facility has a patient navigation program; however, the need is greatest for assisting patients with cancer diagnoses as well as locating patients with very concerning abnormal mammograms who are marginally housed or homeless and difficult to locate. Our results suggest that in addition to needing more research to identify which patient navigation components are most important for which patient populations, there is also a need to create less resource intensive solutions that mammography facilities can employ to decrease delays for the majority of their patients. These solutions may include an electronic tracking system, with ticklers when a patient has not followed-up in a timely manner. However, it will be important not to rely only on an electronic system as electronic reminders to physicians for follow-up of abnormal diagnostic tests have been shown to be inadequate for achieving consistent, timely follow-up.(44) In light of this inadequacy, as well as the documented importance of adequate verbal communication about abnormal mammogram results, it is clear that verbal, human contact between a mammography facility and patient will need to remain a key component in decreasing delays for all women with abnormal mammogram results.

Our study does have limitations. First, we only had administrative language data available from three mammography facilities. These sites have particular characteristics which may limit their generalizability to other facilities. However, our findings highlight the importance of these differences by facility and suggest the need for more detailed understanding of

which characteristics contribute the most to both timeliness and delays in follow-up. Second, we had incomplete biopsy data in earlier years at the two facilities serving the most LEP women, thus we were able to include very few BIRADS 4 and 5 mammograms from those facilities. Lastly, we do not have detailed SES information about the women and thus could not examine patient factors – such as housing, social support, ability to take time off from work – which may differ for women at the different facilities and contribute to the differences in delay among the three facilities. A deeper understanding of the intersection between patient characteristics and facility characteristics and how they interact to contribute to delay may provide insight for the development of future interventions.

Conclusion

In conclusion, we have found that there are considerable differences in delays in diagnostic follow-up of abnormal mammograms, with those facilities serving higher proportions of non-English speaking patients having the longest delays. More attention must be paid to understanding mammography facility factors, such as workload, tracking systems and how patients are informed about results in order to improve rates of timely follow-up, particularly at those facilities that disproportionately serve vulnerable minority and LEP populations and may also disproportionately suffer from budgetary constraints and staffing challenges. Future research should focus on the best practices from the facilities with the lowest delays, as well the intersection of patient and mammography facility factors from those sites with the highest delays. System solutions need to be investigated, such as ways to reduce both wait times to schedule diagnostic mammography as well as radiology workload, while remaining mindful of the need for good verbal communication between provider and patient.

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Figure 1.
Sample selection for cohort of women with abnormal mammograms

Figure 2.
Delays in follow-up for incomplete exams by clinical site

Table 1

Study Population Characteristics for 13,014 Women with Abnormal Mammograms between 1997 and 2008

	Primary Language	
	English N (%)	Non-English N (%)
<u>Language-ethnicity</u>	8,987 (69.1)	4,027 (30.9)
English		
White	4,567 (50.8)	--
African American	1,344 (15.0)	--
Asian	1,399 (15.6)	--
Latino	520 (5.8)	--
American Indian/Alaska Native	39 (0.4)	--
Other/mixed races	784 (8.7)	--
Unknown	334 (3.7)	
Asian languages/Asian Ethnicity	--	1,255 (31.2)
Spanish language/Latino Ethnicity	--	1,910 (47.4)
Russian/various Ethnicities	--	731 (18.1)
Other language/various Ethnicities	--	131 (3.3)
<u>Age</u> Mean, $\pm$ SD (range x-y)	54.2 $\pm$ 11.9 (30-97)	56.9 $\pm$ 12.4 (30-97)
30-39	567 (6.3)	145 (3.6)
40-49	3,019 (33.6)	1,155 (28.7)
50-59	2,841 (31.6)	1,130 (28.0)
60-69	1,421 (15.8)	852 (21.2)
70 and older	1,139 (12.7)	745 (18.5)
<u>Education</u>		
Some high school or less	720 (8.0)	1,598 (39.7)
High school graduate	1,282 (14.3)	769 (19.1)
Some college or technical school	2,061 (22.9)	454 (11.2)
College graduate or more	4,265 (47.5)	753 (18.7)
Unknown	659 (7.3)	453 (11.3)
<u>Index mammogram BIRADS category</u>*		
BIRADS 3	740 (6.6)	403 (8.2)
BIRADS 3+/0	7,262 (65.1)	3,580 (72.4)
BIRADS 4/5	3,163 (28.3)	961 (19.4)

* Groups shown here are not mutually exclusive.

Table 2

Language, BIRADS Category, and Median Time to Follow-up Distribution by Clinical Site

	Site A 3,197 women 3,471 mammos N (%)	Site B 6,669 women 8,609 mammos N (%)	Site C 3,148 women 4,029 mammos N (%)
Language[*]			
English	1,978 (61.9)	5,480 (82.2)	1,529 (48.6)
Asian	153 (4.8)	335 (5.0)	767 (24.4)
Spanish	1,040 (32.5)	171 (2.6)	699 (22.2)
Russian	8 (0.2)	614 (9.2)	109 (3.4)
Other	18 (0.6)	69 (1.0)	44 (1.4)
BIRADS Category[†]			
3 (diagnostic)	80 (2.3)	432 (5.0)	631 (15.7)
3+/0	3,074 (88.6)	4,977 (57.8)	2,791 (69.3)
4/5	317 (9.1)	3,200 (37.2)	607 (15.0)
Median days to first follow-up exam (days)^{‡‡}	25.0	14.0	41.0

* denominator is number of women

† denominator is number of mammograms

‡‡ excludes BIRADS 3 results and mammograms with no follow-up

Table 3

Odds of Delay for Follow-up of Incomplete Mammogram Results by Clinical Site

	Site A		Site B		Site C	
	Language OR (95%CI)	Language & Education OR (95%CI)	Language OR (95%CI)	Language & Education OR (95%CI)	Language OR (95%CI)	Language & Education OR (95%CI)
BIRADS 3+/0						
English speakers	Reference	Reference	Reference	Reference	Reference	Reference
Non-English speakers	1.1 (0.9-1.3)	1.1 (0.9-1.3)	1.6 (1.4-2.0)	2.3 (1.4-3.9)	1.1 (0.9-1.3)	1.1 (0.9-1.3)
Education						
< HS						
>HS		Reference		Reference		Reference
Unknown		1.0 (0.8-1.3)		0.5 (0.3-0.8)		1.0 (0.8-1.2)
		1.7 (1.4-2.2)		0.7 (0.4-1.5)		1.3 (0.8-2.0)