BARRIERS TO BREAST ABNORMALITY FOLLOW-UP: MINORITY, LOW-INCOME PATIENTS' AND THEIR PROVIDERS' VIEW

Little is known about the factors associated with delayed or incomplete adherence to recommendations for follow-up when breast abnormalities are seen in minority women. This study examines barriers to follow-up in a cohort of predominantly minority women, with input from providers, using quantitative and qualitative methods. We conducted telephone interviews with 535 women and in-person, unstructured interviews with 31 providers from three medical facilities in the Los Angeles area. Most patient respondents were <50 years old (59.6%), Latina (84.2%), and unmarried (60.9%); half (49.1%) had six or fewer years of education, and most were foreign-born (83.4%). Data from patient and provider groups identified race/ethnicity, country of birth, financial issues, fear of pain, and difficulty navigating the healthcare system as barriers to follow-up, though certain provider-identified barriers did predict adherence among women. System barriers, not individual patient characteristics, were more salient factors in the follow-up of breast abnormalities. (*Ethn Dis.* 2005;15:720–726)

Key Words: Breast Cancer, Hispanic Americans, Mammography, Patient Compliance

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INTRODUCTION

Although breast cancer is a leading cause of morbidity and mortality among women in the United States, recent statistics suggest a decrease in breast cancer mortality.[1–3] Increased use of screening mammography is given partial credit for improved survival rates, and mammography remains the most effective method for detecting early nonpalpable malignancies, particularly for women ≥50 years.[4,5] Because breast cancer growth rates and aggressiveness vary among patients, and the presence of an abnormality causes patient anxiety, delay in establishing a final diagnosis and instituting therapy can be detrimental.[6–10] Approximately 5% to 10% of all screening mammograms show abnormalities that require surveillance or follow-up treatment[11] and the cumulative risk of an abnormal result after 10 mammograms is close to 50%.[12] Women with clinical breast complaints (eg, breast lumps, pain) are also in need of follow-up, for which a diagnostic mammogram is usually the first procedure.

Despite the importance of timely follow-up, in many cases it is incomplete or delayed.[13–15] This lack of adequate follow-up could be due to any number of factors, such as the physician's lack of appropriate recommendation,[16] patient characteristics,[15,17] and/or institutional barriers.[14] Although researchers have shown an increased interest in the follow-up of abnormal results, little is known about the factors associated with adherence, particularly among minorities.[14,16–18] The few studies that have assessed factors affecting return for follow-up were based on women's perspectives without consideration of providers' input.[14] Research that has been done on screening, or seeking initial care, indicates that greater acculturation is associated with ever having a Pap screening. The perception that the test would be painful and not knowing where to go for the test were negatively associated with ever having a Pap test.[19] Transportation barriers, fear of immigration authorities, perceived control over getting breast cancer, self-rated health status, age, and perceived quality of provider-patient communication are also associated with screening.[20]

The main goal of our study was to assess factors associated with return for follow-up after detecting a breast abnormality in a cohort of primarily low-income Latinas—a unique sample within the literature on this topic—recruited at three medical centers in the Los Angeles area. These factors were examined from two points of view: that of the patients and of the health providers responsible for their care, using both quantitative and qualitative research techniques. The structured survey questions allowed us to quantify and assess a limited number of barriers viewed from the patients' perspective, while open-ended questions in the qualitative interview permitted providers to communicate more than standardized responses, thereby providing an additional point of view and context for the quantitative analysis.

METHODS

Quantitative Survey

This study was implemented at three sites under the jurisdiction of the Los Angeles County Department of Health

Approximately 5% to 10% of all screening mammograms show abnormalities that require surveillance or follow-up treatment.[11]

Services: one hospital and two comprehensive health centers (CHCs). All research procedures were approved by the UCLA Committee on Human Research and by the hospital where the study was carried out.

We identified a cohort of women at these facilities who either had an abnormal mammogram or were referred for a diagnostic mammogram during the study recruitment period. Referrals for diagnostic mammograms were given to women presenting with specific breast complaints (eg, pain, discharge, or a lump) and those with a breast problem identified during a routine examination. Eligible women were identified from radiology appointment logs. Eligibility was defined as any woman who had a breast abnormality identified at any of the three facilities within the study period. Data collection preceded the full implementation of the American College of Radiology (ACR) classification system. Therefore, we used a broad definition of breast abnormality that overlapped with categories III and higher of the ACR classification and included any abnormality defined as "indeterminate" or "suspicious for malignancy," as well as a result leading to a recommendation for follow-up care other than an annual check-up. This definition included dominant masses, multiple masses, asymmetry, calcifications, developing densities, architectural distortion, skin thickening, suspicious calcifications, and suspicions of malignancies. For women who underwent a clinical breast examination, an abnormality was defined as any condition generating a recommendation for a diagnostic mammogram.

The study excluded women whose abnormality was identified at another facility and women with a prior history of breast cancer or a breast abnormality identified less than one year before their index visit. A total of 951 women met the overall study eligibility criteria. Sixty-nine women (7.3%) were deemed ineligible because they lived outside the United States, had language barriers, could not answer the survey, had died, or were incarcerated. Thus, 882 (92.7%) were eligible to participate in the interviews. Of those eligible, 535 (60.7%) completed the interview; interview nonparticipation was due primarily to loss to follow-up (32.8%). Refusal accounted for 5.6% of the eligible sample. Interviews were conducted between January 1995 and February 1996.

Due to the large number of participants, structured questionnaires, rather than qualitative interviews, were administered to assess patients' barriers to follow-up. The questionnaire was prepared in English and then translated into Spanish. The Spanish version of the survey underwent a process of back-translation and group review by a committee of three bilingual research assistants and the senior author. All four members of the committee were from different Latin American countries, which yielded a Spanish survey that would be easily understood by participants from different Spanish-speaking countries. As part of the group discussion, each question was read out loud to make sure that it was understood by all committee members. This process was complemented by a full back-translation that resulted in no major differences between the surveys in the two languages. The few differences encountered were resolved by the senior author. The telephone interview was conducted in English or Spanish, according to participant's preference, and lasted approximately half an hour. All interviewers were female, Latina, and bilingual in English and Spanish.

Demographic indicators from the women's interview included in this analysis were age ($<$50 years, $\geq$50 years), race/ethnicity (Latina; African American; and White, Asian Pacific Islander, or American Indian), marital status (single, married), education ($\leq$6 years, 7–11 years, high school and above), and country of birth (United States, foreign). The linguistic acculturation indicator used in this investigation was based on the acculturation scale developed by Cuellar, Harris, and Jasso[21] and was also used in the Hispanic Health and Nutrition Examination Survey (HHANES). Participants responded to nine items eliciting whether they preferred to speak, read, or write English or Spanish. These items were collapsed into three constructs indicating the language the respondent preferred to speak, read, and write. The language orientation indicator (αreliability=.93) was created by taking a rounded average of these three constructs. Given the distribution of the scale it was dichotomized into Spanish orientation (1) versus English orientation (1.1–3).

In addition, women were asked to report if any of the following situational factors were a barrier to receipt of follow-up care: transportation, clinic distance, household responsibilities, inability to pay, unable to take time off from work, or concerns about pain. All barriers were dichotomous and reported as existing or not. System barriers to follow-up care were also assessed. Respondents were asked whether they had knowledge about the type of doctor or clinic to go to. Three potential barriers were identified to examine patient satisfaction with medical care. Patients were asked to state their satisfaction (very satisfied, somewhat satisfied, or not satisfied) with their wait time to get an appointment, wait time to receive care, and the clinic's hours. These factors were associated with adherence behavior in prior research on follow-up of cervical abnormalities.[20,22]

Qualitative Interviews

In addition to patient participation, we contacted healthcare professionals and support personnel who were associated with the three participating medical centers and involved in follow-up care for women with breast abnormalities. Our aim was to ascertain their perspectives about barriers to follow-up with semi-structured, in-person interviews. We used a snowball sampling technique[23] to identify not only physicians and nurses, but ancillary personnel involved in follow-up care, such as receptionists, administrative staff, radiology technicians, and social workers. Each face-to-face interview lasted approximately one hour.

The qualitative semi-structured interview format was chosen to gain more detailed information from providers, as we could not obtain meaningful quantitative data from the limited number of provider participants available. We constructed an open-ended interview guide to elicit providers' opinions, and questions were intentionally undirected, so that the providers could tell in their own words how they perceived the barriers to follow-up.

Interviews were conducted with 31 healthcare personnel involved in the follow-up process: radiologists (11), radiology technicians (5), nurses (7), support personnel (7), and a social worker (1). Most healthcare providers (23 out of 31) were female, including all nurses, all support staff, the social worker, and all but one technician. Of the physicians interviewed, 7 of 11 were male. Interviews were audiotaped and later transcribed verbatim. The transcripts were analyzed by using a qualitative data analysis program, The Ethnograph (Qualis Research Associates, Denver, Colorado). Interviews were coded with selected interviewee characteristics (clinic, job title, and gender), and sections of text were assigned codes to describe content. Core and other emergent code categories were generated through repeated readings. The data were then sorted by text codes and linked with the interviewee's characteristics. We explored patterns of response by clinic, job title, and gender; analyzed the range of responses; and identified recurrent themes. This process was iterative in that analysis raised further questions for exploration, which required new coding, sorting, and analysis.

RESULTS

Quantitative Survey

Table 1 includes the demographic characteristics of the patient population based on interview data.

Qualitative Interview

The items identified by healthcare providers as potential barriers to follow-up were grouped into the three thematic areas of patient characteristics, situational barriers, and system barriers. For each area, we present a summary of ideas volunteered by providers.

Patient Characteristics

Providers identified certain characteristics of their patient population that they believed were deterrents to follow-up. These included age, culture/ethnicity, and country of birth/immigration status/mobility.

Although many providers believed that age was a factor, they disagreed as to which age group was less likely to return for treatments. Overall, older women were perceived as less likely to be adherent than younger women. Staff felt that older women considered themselves too old to worry about cancer. In contrast, some providers thought that older patients were more likely to return, saying that "they all tend to be religious about keeping their appointments."

Providers ascribed patient adherence or lack thereof to cultural characteristics and recognized that the cultural differences that existed between themselves and their patients might affect patient care. Providers also identified positive influences of culture on adherence, such as strong feelings about family obligations.

Providers commented on the makeup of their patient population—predominantly foreign born—postulating that they were less adherent than US-born patients. They hypothesized that some portion of these patients may not be permanent, legal residents of this country and that a patient's illegal immigration status and fear of being reported might adversely affect adherence. At the end of 1995, when most of the interviews took place, California voters had just approved Proposition 187, which required medical facilities to request proof of US residence from patients. When questioned about Proposition 187, providers indicated that they believed it affected adherence because some patients were afraid they would be deported if they came in for services.

Almost all providers mentioned that inability to locate patients was a main reason for lack of adherence. They conjectured that undocumented residents were afraid to give correct addresses. Providers also identified that high patient mobility affected their ability to contact patients. Patients' frequent relocation or extended visits to their country of origin could result in the clinic's having an incorrect address. Clinics make an effort to try to reach patients, and providers acknowledged the time and cost of doing so.

Situational Barriers

Providers identified several barriers to follow-up that were specific to their patients, such as fear of procedures and/or results, transportation issues, financial barriers, or other responsibilities that might prevent them from keeping follow-up appointments.

Providers described how news of a breast abnormality could evoke con-

Table 1. Factors affecting return for follow-up—patients' perspectives

	N=535	Did Not Return (8.6%)	Returned (91.4%)
Patient characteristics			
Age			
<50	319 (59.6)	7.2	92.8
≥50	216 (40.4)	10.6	89.4
Race/ethnicity*			
Latina	447 (84.2)	7.6	92.4
African American	42 (7.9)	14.3	85.7
Asian American	15 (2.8)	6.7	93.3
White	26 (4.9)	11.5	88.5
American Indian	1 (0.2)	–	–
Marital status			
Not married	326 (60.9)	8.9	91.1
Married	209 (39.1)	8.1	91.9
Education			
≤6 years	260 (49.1)	8.8	91.2
7–11 years	124 (23.4)	5.6	94.4
≥High school	146 (27.5)	9.6	90.4
Country of birth*			
Foreign	441 (83.4)	7.5	92.5
United States	88 (16.6)	14.8	85.2
Language orientation (only among Latinas)			
Spanish	368 (68.1)	7.3	92.7
English	86 (16.1)	11.6	88.4
Situational barriers			
Transportation			
No	424 (81.1)	7.3	92.7
Yes	99 (18.9)	13.1	86.9
Clinic distance†			
No	416 (79.5)	6.7	93.3
Yes	107 (20.5)	15.0	85.0
Household responsibilities			
No	426 (79.6)	8.0	92
Yes	109 (20.4)	11.0	89.0
Inability to pay†			
No	458 (87.6)	7.2	92.8
Yes	65 (12.4)	16.9	83.1
Unable to take time off work			
No	441 (89.8)	7.9	92.1
Yes	50 (10.2)	12.0	88.0
Concerns about pain*			
No	462 (88.5)	9.3	90.7
Yes	60 (11.5)	1.7	98.3
System Barriers			
Knowledge of type of doctor/clinic to go to*			
No	463 (88.7)	7.3	92.7
Yes	59 (11.3)	16.9	83.1
Satisfaction with time to get appointment			
Somewhat or not satisfied	292 (57.5)	7.9	92.1
Very satisfied	216 (42.5)	8.8	91.2
Satisfaction with waiting time for care			
Somewhat or not satisfied	289 (56.4)	9.0	91.0
Very satisfied	223 (43.6)	7.6	92.4
Satisfaction with clinic hours			
Somewhat or not satisfied	130 (25.7)	11.5	88.5
Very satisfied	376 (74.3)	7.7	91.3

* $P<.05$; † $P<.001$.

cern and fear in patients, possibly causing non-adherence. Furthermore, they recognized that receiving the information by mail might add to the anxiety and reported that alarmed patients usually called the facility requesting assurance and additional information not provided in the letter. Despite these patient concerns, providers reported being generally unable to provide that type of information over the telephone.

Lack of transportation was mentioned by several providers.

Financial barriers affect the ability to seek medical care, including return for follow-up appointments.[18,24,25] Providers recognized this as a common barrier and were aware that, despite the availability of a special payment plan, patients may not be able to pay.

Latina women are often responsible for household maintenance and the well-being of the family,[26] activities that may interfere with their self-care. They also may face difficulties with taking time off work.

System Barriers

Providers spent a large proportion of their interviews identifying system-related barriers that they believe hinder return for follow-up treatment. Among the most frequently cited were lack of a protocol for follow-up of breast abnormalities, issues of scheduling, and insufficient clinic hours.

The follow-up for breast abnormalities often involves the coordinating services among several clinics, including the referring clinic, radiology, and specialty breast and tumor clinics at different levels of care (ie, the CHC and hospital level). No single person at any of the sites coordinated all follow-up activities or assisted patients in navigating multiple clinics. This difficulty navigating the system was viewed as a deterrent to patient adherence.

Providers recognized that the length of time a woman has to wait to get an appointment and waiting time at the clinic site were barriers to receiving care. Despite efforts to reduce waiting time, some women had to wait a month for a follow-up appointment. The number of missed appointments creates additional problems. In some facilities, women had to be rescheduled three times for follow-up.

Identified as physician-centered rather than patient-oriented, limited clinic hours were viewed as being partially responsible for the high rate of non-adherence or the high proportion of patients who needed to reschedule appointments. Facilities usually hold clinic hours during the day without offering late afternoon or Saturday appointments. Lack of extended or flexible clinic hours was perceived to particularly affect women who work. Many patients may be employed in low-paying jobs without health insurance and other benefits, such as sick leave, that would allow them to attend daytime clinics.

Table 2 compares qualitative results from physician interviews with quantitative results from the patient survey.

Table 2. Barriers to follow-up, providers' and patients' perspectives

	Providers' Perspective Qualitative Interviews (n=31)	Patients' Perspective (Statistically Significant) Quantitative Survey (n=535)
Patient characteristics		
Age	YES Conflicting opinions about which group more adherent	NO
Race/culture/ethnicity	YES Belief that Latinas are less adherent	YES Non-Latina White women less adherent
Country of birth	YES Belief that foreign born are less adherent	YES US-born women less adherent
Immigration status/mobility	YES Belief that non-US citizens are less adherent	Not asked
Situational barriers		
Fear of procedures/results	YES	Not asked
Concerns about pain	YES Belief that patients concern about pain less adherent	NO Patients not concerned about pain less adherent
Transportation	YES	NO
Clinic distance	Not discussed	YES
Inability to pay	YES	YES
Household responsibilities	YES	NO
Employment responsibilities	YES	NO
System barriers		
Difficulty navigating the system	YES	YES
Scheduling/wait time until appointment	YES	NO
Waiting time to be seen by provider	YES	NO
Clinic hours	YES	NO

DISCUSSION

With respect to characteristics of patients, only race/ethnicity and country of birth were found to be significantly associated with adherence. Providers strongly considered the women's cultural milieu when assessing adherence. Specifically, a patient's ethnicity (in this case, Latina) and immigration status were thought to be likely deterrents to return to follow-up. However, our data indicate that Latinas were more likely to return than non-Latina women. As for country of birth, most women in our sample were foreign-born, reflecting the providers' correct perception about the make-up of their patient population; however, contrary to their perception, foreign-born women were more likely to return for follow-up than those born in the United States.

Issues of ethnicity and country of origin play an important part in the delivery of care and were widely recognized by providers as factors affecting adherence.[27–30] However, in our study, the absolute number of non-Latina women attending these facilities was small, which may have masked the problem that, in actuality, a large proportion of them did not return for follow-up. In turn, Latinas and foreign-born women who attended the facilities in greater numbers were perceived as less adherent, despite evidence to the contrary. Although non-Latina, US-born women were less likely to return for follow-up, these women may have received care at some other facility.

Providers' perceptions and patient survey data were in accord on one situational barrier related to adherence: inability to pay. Although only 12% of women identified inability to pay as a barrier to care, those who cited financial barriers were more than twice as likely not to return for follow-up as other women. Providers in this study recognized this as a common barrier. As part of a special payment plan instituted at the facilities where we recruited participants, patients could pay a fixed amount per visit if they were not insured or could not pay the full price for services. In spite of being eligible for this reduced fee, for some patients even this amount might have been too much to pay, which would affect their follow-up care.

Another situational barrier examined, concern about pain during follow-up visits, was mentioned by providers as a possible deterrent to returning

Specifically, a patient's ethnicity (in this case, Latina) and immigration status were thought to be likely deterrents to return to follow-up.

for follow-up and was identified as a barrier by some of the women interviewed. However, women who cited pain as a barrier were more, rather than less, likely to return for follow-up. This counterintuitive finding may be due to the fact that women who returned for follow-up were more likely to experience pain while undergoing follow-up treatments and expressed their discomfort at the time of the interview.

The notion that women might fear the results of follow-up procedures was discussed by providers, but women were not queried about this barrier. According to providers' comments, many women express their concerns to their physicians or related personnel about their follow-up procedures and fear of possible cancer. Future research in this area might enhance our understanding of the role of fear in adherence to follow-up.

Providers mentioned transportation as a barrier, as did nearly 20% of women, but this factor did not achieve significance as a predictor of return for follow-up. A related barrier, clinic distance, did prove significant. The neighborhoods where these women reside or work do have the public transportation resources necessary to reach the facilities; however, the length of travel time necessary to attend distant clinics may affect access to care.

Household and employment responsibilities were also viewed as deterrents by providers. Household responsibilities were the second most-cited barrier in the women's survey, correctly reflecting the providers' awareness of their patients' concerns. However, it was not a significant predictor of adherence. A smaller proportion of women cited that they were unable to take time off work, but this, too, did not significantly predict adherence. This finding suggests that although women face obstacles at home and in the workplace, they manage to overcome these difficulties to return for care and resolve the issues raised by the discovery of a breast abnormality.

Our aim was to use both qualitative and quantitative research techniques to enhance our understanding of adherence behavior. We assert that using this combined method of study can aid in the comprehension of individual events and deepen the understanding of health behaviors. For example, most women were not satisfied with appointment and clinic wait times, and providers validated this problem, providing context and reasons why appointment and clinic wait times were so long. Qualitative interviews revealed that providers believed that several of the patient characteristics, such as age and cultural background, strongly affected follow-up care, but patients' interviews suggested a different emphasis. While individual factors such as race/ethnicity and birth country can affect follow-up, situational and system-related barriers were the primary factors. A quantitative analysis of results from the women's survey revealed that some of the factors discussed by providers were either not significant in the direction believed or were not significant at all. Results from the quantitative method validated some of the providers' comments, while also calling into question many of the providers' beliefs. On the other hand, the providers' interviews highlighted new areas, such as fear of test results or immigration status, that need to be addressed in future studies.

These findings suggest some recommendations for medical practice and health education. In general, providers agreed that patients should receive more information and education regarding breast cancer, breast abnormalities, and follow-up procedures. Patients should be informed of specific reasons why return for follow-up is necessary, in part so they have greater motivation for overcoming the system barriers that make adherence a challenge. Providers felt that a better system was needed to guide patients through the follow-up process and coordinate the activities of the referring clinics and specialty clinics. Women also reported that a lack of information about physicians or clinics actually prevented some of them from obtaining their follow-up treatment. This finding suggests that both provider/patient communication about follow-up activities and the referral process could be improved. Providers' willingness to participate in the study suggests motivation to improve services.

The limitations of this study must be acknowledged. First, the results concerning return for follow-up may not be easily generalized to other populations or other healthcare settings, as our sample was recruited from county facilities in a large metropolitan area. However, these findings may be broadly applied to low-income Latinas receiving care in large, urban, public facilities throughout the United States. This research also highlights important areas to explore in future research, such as the impact of patients' fear of a cancer diagnosis on adherence to follow-up endeavors. Comparison of patients' and providers' explanatory models of barriers to care would help us design systems that would enhance adherence to follow-up.

Despite these limitations, however, our overall findings suggest that situational and system-related variables, rather than patient characteristics, are significant barriers to follow-up for this patient population. While we acknowledge that cultural and individual factors can affect follow-up behavior, the weight of the evidence from this quantitative/qualitative study points to access to care issues—economics, distance, and ability to navigate the healthcare system—as the salient factors affecting follow-up. Because breast cancer is a life-threatening disease, women are inclined to seek follow-up care as long as access to it is not limited.

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