Manuscript Title: Misconceptions about breast lumps and delayed medical presentation in urban breast cancer patients.

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Condensed abstract: In a population-based study of urban breast cancer patients, 16% reported delaying seeking medical attention for more than three months. Misconceptions related to when a breast lump should receive medical attention were prevalent among ethnic minorities and women of lower socioeconomic status and strongly associated with greater delay in seeking medical attention following discovery of a lump.

ABSTRACT

BACKGROUND: Despite current recommendations for women to be screened for breast cancer with mammography every one to two years, less than half of all newly diagnosed breast cancers are initially detected through screening mammography. Prompt medical attention to a new breast symptom can result in earlier stage at diagnosis, yet many patients delay seeking medical care after becoming aware of a breast symptom. METHODS: In a population-based study of breast cancer we examined factors potentially associated with patient delay in seeking health care for a breast symptom among 436 symptomatic urban breast cancer patients (146 White, 197 Black and 95 Hispanic). Race/ethnicity, socioeconomic status, health care access and utilization, and misconceptions about the meaning of breast lumps were the key independent variables. RESULTS: Sixteen percent of patients reported delaying more than 3 months before seeking medical advice about breast symptoms. Misconceptions about breast lumps, and lacking a regular provider, health insurance and recent preventive care were all associated with prolonged patient delay (p<0.005 for all). Misconceptions were much more common among ethnic minorities and women of lower socioeconomic status. CONCLUSION: Reducing patient delay and disparities in delay will require both educating women about the importance of getting breast lumps evaluated in a timely manner, and providing greater access to regular health care.

INTRODUCTION

Screening for breast cancer with mammography is the only widely accepted method for the early detection of breast cancer, and secular increases in mammography screening utilization have been linked to a shift towards earlier stage at diagnosis (1). Despite current recommendations for women to get screened every one to two years, many women are not screened and some women who are screened develop symptoms of breast cancer despite a recent screen. As a result, less than half of all newly diagnosed breast cancers are initially detected through screening mammography (2-5).

Delays in seeking medical care after becoming aware of a breast symptom may lead to later stage at diagnosis (6,7) and has been associated with shorter survival time after diagnosis, although this may reflect a lead time bias rather than an actual improvement in survival (8). Understanding the factors that contribute to delay in seeking medical evaluation is critical for the development of interventions to reduce delay. Prior studies have estimated that approximately one third of women experiencing symptoms of breast cancer delay seeking help for at least 3 months and approximately 25% of women will delay six months or longer (6,9). Among poor or minority populations, the percent of women who delay at least 3 months may be as high as 45 percent (10).

In this study, we examine the factors that affect prolonged patient delay following self-discovery of a breast lump or symptom among non-Hispanic White, non-Hispanic Black and Hispanic urban breast cancer patients. Patient delay was defined as the time elapsing between symptom self-discovery and first attempt to contact a medical provider. This definition differs from others in the literature that define the endpoint for delay as the presentation to a medical provider. We chose the more conservative definition because getting an appointment with a provider is

affected by more than patient delay, such as availability of appointments which is beyond the control of the patient.

MATERIALS AND METHODS

Sample and Procedure

Eligible female patients were between 30 and 79 years of age at diagnosis, resided in Chicago, had a first primary in situ or invasive breast cancer, were diagnosed between 2005 and 2008, and self-identified as either non-Hispanic White, non-Hispanic Black or Hispanic. All diagnosing facilities in the greater Chicago area (N=56) were visited on a monthly basis and all eligible newly diagnosed cases were ascertained. Certified tumor registrars employed by the Illinois State Cancer Registry (ISCR) reviewed pathology records, the hospital tumor registry or both, depending on the protocol at the individual hospital. Information on patient race and ethnicity were sought from the patient's medical record when not available in the hospital tumor registry. A file containing all eligible patients including information on race/ ethnicity and facility of diagnosis was created and used to develop analytic weights to account for differential sampling and response by facility and race/ethnicity.

A letter describing the study and a recruitment brochure were mailed by ISCR to each eligible patient between 1-3 months after initial diagnosis (in both Spanish and English if ethnicity was unknown or known to be Hispanic). If a patient did not respond either by mail or telephone within 10 days, a second contact was attempted by mail, telephone, or both. Once contact was established, if the patient expressed interest in participating in the study, she was placed in contact with the UIC Survey Research Laboratory where she was screened for eligibility and scheduled for an interview. If the patient said she was not interested, the case was flagged for recontact 2 months later, allowing the patient more time to adjust to her diagnosis. The survey interviewer obtained written informed consent before the interview was administered. As part of

the consent process, patients were informed they would receive a gift of $100 for their participation. The 90 minute interview was administered either in English or Spanish as appropriate using computer-assisted personal interview (CAPI) procedures. The final interview response rate was 56% (989 completed interviews among eligible patients).

Measures

The interview queried subjects about the process of discovery, diagnosis and treatment of the patient's breast cancer, as well as health care seeking behavior and related constructs. Patients were asked how they first became aware of the problem later diagnosed as breast cancer. Forty-five percent of patients in the study (N=441) reported that they had self-identified the symptom that led to the initial discovery of the breast cancer (38% of non-Hispanic White, 47% of non-Hispanic Black and 55% of Hispanic patients, p=0.0002). For these analyses, only patients with a symptomatic breast cancer were included. The extent of patient delay was determined from the following series of questions:

> "When a woman discovers a problem in her breast, she usually has to think about what to do next before contacting a doctor. What about you? Please think about how much time passed after you noticed a lump before you first contacted a doctor. Did you make an appointment the same day, the next day, within a week of finding the problem, or was it more than a week?"

Patients had the option of reporting extent of delay in days, weeks, months or years, and all responses were converted to days. From this variable, a dichotomous variable was created as 90 days or less versus more than 90 days (prolonged patient delay). The justification for dichotomizing delay at 90 days was based on previously published findings that patients with total delays of less than three months have significantly better 5-year survival than those with delays of three to six months (8). Responses by 12 percent of patients could not be coded to

the nearest month; however, all but two patients provided enough information to enable their responses to be coded as either 3 months or less or greater than 3 months. The final sample for analysis was 436.

Conceptual model for prolonged patient delay

Figure 1 presents a conceptual model for prolonged patient delay that builds upon a model for stages of delay presented in Anderson et al. (1995) (11). The Anderson model is a general model for total patient delay from initial detection of the problem through treatment initiation. The first two stages of delay (appraisal delay and illness delay) are applicable to our study of patient delay before deciding to seek help for a breast problem. Appraisal delay is defined as the number of days from initial detection of the problem to when the patient infers that she is ill. Illness delay is defined as the number of days from illness inference to deciding to seek help. Subsequent stages of the Anderson et al. model (behavioral delay, scheduling delay and treatment delay) are not applicable here to our analysis of patient delay. Superimposed over the Anderson model are the measured variables in our study, which are enclosed in boxes (Figure 1). We conceptualize our measured variables in three broad groups: sociodemographic variables, variables pertaining to the interpretation of symptoms, and variables pertaining to access and utilization of health care. In this model, sociodemographic variables affect delay primarily by influencing either symptom interpretation or access to care. Within the symptom interpretation box, we conceptualize that misconceptions about the meaning of breast lumps would impact whether a woman feels the need to present medically, and that woman with a personal history of benign breast problems (i.e. who experienced a false alarm in the past) might be more likely to hold these misconceptions and therefore be less likely to present promptly the next time she finds a symptom. A family history of breast cancer might prompt a woman with a self-discovered symptom either to seek help sooner or delay seeking help to avoid a diagnosis of breast cancer. Within the health care access and utilization box, we

conceptualize that absence of insurance may lead to absence of a regular provider, and that both of these variables would lead to fewer preventive care visits (Figure 1). We also assume that how a woman interprets symptoms primarily influences appraisal delay, whereas health care access variables primarily influence illness delay. It is important to note that we were unable to examine these last two assumptions because our variable for patient delay did not differentiate between these two components.

Measures of sociodemographic characteristics

Demographic information included race/ethnicity, age, and education.. Patients were categorized as 1) White, non-Hispanic, 2) Black, non-Hispanic, and 3) Hispanic or Latino. Ethnicity was defined through separate self-identification of Hispanic ethnicity and race. Ethnicity was defined as Hispanic if the patient self-identified as Hispanic, reported a Latin American country of origin, or reported a Latin American country of origin for both biological parents. Reported level of education was used to create a binary variable for absence of a high-school degree, and reported annual household income was used to create a binary variable for low income, defined as below $20,000.

Measures of health care access, utilization, and trust

Patients who reported a usual place for care (regardless of whether they reported a regular provider) were asked to consider the statement "In general, I trust this place to provide me with the best possible health care" and report whether this was always true, mostly true, half the time true, sometimes true, or never true. From this question we defined a binary variable such that patients reporting the statement as always or mostly true were defined as having higher trust than patients reporting this statement to be less often true. Health insurance status was categorized as no insurance, public but not private insurance, and private insurance. Patients enrolled in Medicare Part A but not Part B were categorized as uninsured, since they lacked the

applicable outpatient benefit that would influence delay. Medigap coverage with Medicare was defined as private insurance. Patients were asked: "think back to the time before the problem was discovered that turned out to be cancer. Around that time, did you have a doctor or health care person that you thought of as your own doctor, someone you went to regularly for care?" Patients were also asked, "When had been your last routine physical examination, when you had to get undressed and a medical person examined you from head to toe? Was it within 12 months, 2 years, or more than 2 years before this time?" In addition, patients were asked "had you ever had a clinical breast exam, when your breasts are checked for lumps by a doctor or nurse?" followed by (if applicable) "Do you remember if your last breast exam was within 12 months, 2 years, or more than 2 years before you found the problem that turned out to be cancer". Similar questions were asked to gauge recency of mammography prior to discovery of the problem. From these questions, three binary variables were defined (one each for routine physical, clinical breast exam and mammography) such that patients who reported an exam within one or two years prior to discovery of the problem were defined as having a recent exam. The number of patients who did not report either the presence or timing of their last routine physical, clinical breast exam, and mammogram, was 0, 2, and 2, respectively; these patients were coded as not having a recent exam. These three recency of care variables were strongly correlated with each other (r = 0.34 - 0.53) and were used to create a "recency of care" score with a Cronbach's alpha of 0.71, and a range from 0 to 3.

Factors influencing symptom interpretation

A woman was defined as having a history of benign breast problems if she reported having past breast problems and/or a prior breast biopsy. First-degree family history of breast cancer was defined as none, moderate (one affected relative diagnosed at or above age 50) and strong (multiple affected relatives or one relative diagnosed before age 50). Cultural myths about breast lumps were examined using three questions: "You only need to get a breast lump

checked for cancer if it is painful"; "You only need to get a breast lump checked for cancer if it gets bigger"; and "If a breast lump is touched or pressed often, the lump will turn out to be breast cancer". Patients were asked to respond whether they believed these statements to be true or false. These items were selected from a larger 17-item general scale of cultural beliefs about breast cancer (12) because we hypothesized that women holding these beliefs would have longer delay. These questions were strongly correlated with each other (ρ = 0.33-0.62) and were used to create a mini-scale with a Cronbach's alpha of 0.72.that ranged from 0 to 3.

Statistical analyses

First, we examined the percentage of women with prolonged patient delay (more than 90 days from symptom discovery to seeking medical care) within categories of demographic, health care access and attitudinal variables and the corresponding p-values from chi-square tests for homogeneity. Next, we constructed a predictive logistic regression model of prolonged patient delay using a stepwise selection procedure with a liberal p-value of 0.20 to enter and stay in the model (13). All analyses were conducted using SAS version 9.1 (SAS Institute, Cary NC). Analytic weights were included in logistic regression models in order to account for differential participation by race/ ethnicity and facility of diagnosis.

RESULTS

Distribution of patient characteristics

Of the 438 patients in this study with symptomatic discovery of their breast cancer and information on patient delay, 16% reported prolonged patient delay of greater than three months. Nearly half of patients in this study who reported symptomatic discovery of their breast cancer were African-American; two-thirds of Hispanic patients reported Spanish as their primary

language. Approximately one in five patients were without public or private health insurance, and similar proportions were lacking a regular provider and reported lower levels of trust in their providers. Regarding recency of routine care, 70%, 65% and 51% reported a routine physical exam, clinical breast exam and mammogram within the last two years, respectively. Each of the three misconceptions regarding breast lumps was endorsed by roughly one in ten women, and one in five reported believing one or more of these misconceptions (Table 1). Nearly one half of patients reported having a prior history of breast problems.

Patient characteristics as predictors of prolonged patient delay

There were no significant differences in delay by demographic characteristics. Contrary to expectation, African-American and Hispanic patients were not more likely than White patients to report prolonged delay (Table 1). However, the three misconceptions about breast lumps were significantly associated with prolonged patient delay: "You only need to get lump checked if painful" (38% vs. 14%); "You only need to get lump checked if gets bigger" (28% vs. 14%); and "Pressing a lump will cause it to be breast cancer" (30% vs. 14%). The proportion of patients reporting prolonged patient delay increased from 14% to 36% as the number of reported misconceptions increased from 0 to 2 or more (Table 1).

Greater health care access and utilization was significantly inversely associated with prolonged patient delay. Thirteen percent of those with private insurance delayed compared with 24% of those with no insurance and 21% of those with only public insurance (p=0.006). Eleven percent of those with a regular provider reported prolonged patient delay compared with 37% of those without a regular provider (p<0.0001). Only 10% of patients reporting a routine physical in the past two years delayed compared with 30% of patients without a recent physical (p<0.0001). Similar differences in prolonged patient delay were observed with respect to time since last clinical breast exam and mammogram (Table 1). A history of benign breast problems was not

associated with delay; neither was first-degree family history of breast cancer. When mutually

adjusted in logistic regression, , a greater number of misconceptions about breast lumps,

absence of a regular provider, and lower recency of care score (sum of recent routine physical,

clinical breast exam and mammogram) were each significantly associated with prolonged

patient delay, while older age was marginally associated with delay (Table 2). In addition, a

history of past benign breast problems became associated with prolonged patient delay when

adjusted for other patient characteristics (Table 2).

Misconceptions about breast lumps

Misconceptions about breast lumps were much more common among women who are typically

defined as disadvantaged: ethnic minorities with lower socioeconomic status and less access to

care (results not tabulated). AA and Hispanic women were considerably more likely to report a

breast lump misconception than Whites (18% and 38% vs. 5%, p<0.0001). The probability of

holding one or more misconceptions about breast lumps increased with increasing age

decreasing education (p <0.0001), decreasing income (p <0.0001), lack of private health

insurance and lack of a regular doctor (p <0.0001 for each)..

DISCUSSION

In a systematic review of studies published between 1907 and 1996, Richards et al. found that

longer delay was associated with later stage at diagnosis and shorter survival for breast cancer

(8); their interpretation was that the effect of delay on survival could only partly be explained by

lead-time bias. While the effect of delay on survival has not been clearly established, the effect

of longer delay on increased stage at diagnosis (and therefore also on stage-related treatment

morbidity) has been established, and the discovery by a woman of a new breast lump or other

suspicious symptom requires prompt attention. Understanding the barriers to prompt medical

presentation of suspicious breast symptoms would enable strategies to be developed to reduce

delays. Longer patient delay has been associated with Black or Hispanic ethnicity and low socioeconomic status in other studies (7,9,14). Contrary to these prior studies, we did not find significant associations between race/enthicity, education, or income and prolonged delay. We anticipated that AA and Hispanic women in our study would be more likely than their White counterparts to report prolonged patient delay, yet such a racial and ethnic disparity was not evident. Our results suggest that there are no racial/ethnic differences in the extent of patient delay among breast cancer patients in this urban population. Another possibility for these findings, however, is that an actual disparity in delay might have been masked by a greater tendency for socially desirable reporting among ethnic minorities compared to Whites (15). Studies comparing self-reported breast and cervical cancer screening to medical records documentation have revealed that African-American and Hispanic women are more likely to "forward telescope" the date of their most recent screening examination, resulting in a greater tendency to over-report their recent screening history compared to Whites (16-17).

We estimated disparities in prolonged patient delay by education and income that were more modest than we had anticipated. Disparities related to socioeconomic status may also have been masked by a greater tendency for over-reporting among patients of lower socioeconomic status. Results from a study comparing self-reported mammography use to claims among Medicare recipients suggest that a tendency for providing socially desirable responses may be more pronounced not only among minorities but also among women with lower education and lower income (18). If the same mechanism is at work when reporting the extent of delay, then it is possible that larger disparities in prolonged delay by education and income were being masked by differential reliability of reporting.

We found that greater health care access and utilization were strong predictors of reduced patient delay in this urban setting. Having health insurance, a regular doctor and more recent mammography, clinical breast exam and routine physical examination were each associated

with reduced likelihood of prolonged patient delay. Few other studies have examined the role of health care access and utilization in patient delay following discovery of a breast symptom. In contrast to our findings, a single large urban study (n=692) found no evidence linking a woman's mammography screening history to delay (19). However, this study was conducted in a London based clinic, in which women received care within the United Kingdom's publicly-funded health care system. Thus, the differences in findings between these two studies are likely due to differences in health care systems.

Our results also highlight the importance of misconceptions about breast lumps in contributing to longer delay. Holding a misconception about breast lumps was strongly associated with prolonged patient delay. In addition, misconceptions about breast lumps were much more common among women who are typically defined as disadvantaged: ethnic minorities with lower socioeconomic status and less access to care.

Limitations

There were several study limitations that are worth noting. As mentioned above, the outcome representing patient delay following symptomatic discovery was based entirely on self-reported passage of time. Reliance on self-report for this information is unavoidable for any study of patient delay, since any information regarding the development or discovery of a lump or other breast symptom must start with awareness by the patient. Therefore, any documentation of patient delay (e.g. in the medical record) would ultimately have been the result of a patient self-report.

In addition, the response rate for this study was 56%, meaning that nearly half of eligible patients in our study (both symptomatic and screen-detected) chose not to participate. Participants and non-participants were not different with respect to information available on staging during case ascertainment (which tends to underestimate final pathologic stage at

diagnosis). Participants were more likely than non-participants to be AA (41% vs. 32%) or Hispanic (16% vs. 13%), and participants tended to be younger than non-participants (mean age 57 vs. 61 years, p<0.0001). It was not possible to calculate the response rate specifically for symptomatic breast cancer patients. We developed and used analytic weights in our models in order to partially account for differential sampling and participation by facility and by race/ethnicity. Non-participants in health-related studies are generally less health conscious and less likely to participate in preventive health care (20-22), and these same patients may be less likely to seek timely medical care for suspicious breast symptoms. Consistent with this, lower health care access and utilization, was associated with prolonged patient delay in our study. It is unclear the extent to which differential participation may have attenuated or inflated associations of interest, but it is unlikely that this would obviate the more notable associations found in this study regarding misconceptions about breast lumps and health care access and utilization, with prolonged patient delay.

Misconceptions about breast lumps, and reduced access to health care were each associated with prolonged patient delay in our study. Misconceptions were much more common among ethnic minorities and women of lower socioeconomic status. Many women who hold misconceptions are potentially eligible for free mammograms under the National Breast and cervical Cancer Control Program (NBCCCP). A multi-faceted intervention could be developed to simultaneously increase access and reduce misconceptions. Women could be enrolled into the program as part of a larger intervention that included educating women more generally about the need to get screened and to monitor for lumps and other potential symptoms of breast cancer.

Table 1. Distribution of patient characteristics and crude associations with delayed medical presentation (>90 days) among women with symptomatic breast cancer

	N	%	% Delayed[1]	P-Value
Demographics				
Age				
<50	180	41	13	
50-59	144	33	18	
60 and above	112	26	18	
Race/Ethnicity				
Non-Hispanic White	145	33	15	
Non-Hispanic Black	197	45	16	
Hispanic	94	22	18	
Education				
< High School	80	18	21	0.08
High School	105	24	19	
> High School	251	58	14	
Annual Household Income				
<=30,000	175	41	19	0.14
30,001-75,000	155	36	14	
>75,000	100	23	13	
Married / living as married				
No	178	41	19	0.11
Yes	258	59	14	
Interpretation of Symptoms				
Family history of breast cancer				
None	344	80	15	
Moderate	63	14	22	
Strong	25	6	17	
History benign breast problems				
No	246	56	14	
Yes	190	44	18	
Misconceptions about breast lumps				
Only need to get lump checked if painful				
False	404	92	14	0.0002
True	34	8	38	
Only need to get lump checked if growing				
False	388	88	14	0.01
True	50	12	28	
Pressing will cause it to be breast cancer				
False	393	90	14	0.009
True	44	10	30	
Number of misconceptions (0-3)				
0	357	82	14	0.0008
1	47	11	23	
2+	32	7	36	
Health care access and utilization				
Health Insurance				
None	82	19	24	0.03
Public, no private	73	17	21	
Private	281	64	13	
Regular provider				
No	92	21	37	<0.0001
Yes	344	79	11	
Trust in routine care place[2]				
Sometimes, rarely or never	51	13	20	0.02
Always or mostly	342	87	12	
Routine physical within 2 years				
No	133	30	30	<0.0001
Yes	303	70	10	
Breast exam within 2 years				
No	150	35	32	<0.0001
Yes	284	65	8	
Mammogram within 2 years				
No	215	49	25	<0.0001
Yes	220	51	8	
Recency of care score				
0	82	19	34	<0.0001
1	70	16	26	
2	112	26	13	
3	174	40	5	

[1] Weighted to account for differential sampling and participation by facility and race/ethnicity. [2] 43 patients without a regular source of care are coded as missing on this variable. P-values >0.20 are not shown.

Table 2. Final model of patient characteristics associated with prolonged patient delay, defined as greater than 90 days (N=436).

	OR (95% CI)	p-value
Age in decades	1.27 (0.98, 1.64)	0.07
Misconceptions about lumps (0-3)	1.82 (1.18, 2.78)	0.006
Regular provider	0.33 (0.17, 0.63)	0.0008
Recency of care score (0-3)	0.53 (0.40, 0.69)	<.0001
Past benign breast problems	1.96 (1.09, 3.51)	0.02

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FIGURE 1. Conceptual model for prolonged patient delay before deciding to seek help for a breast problem