



Breast cancer screening practices among American Indians and Alaska Natives in the Midwest

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ABSTRACT

American Indian and Alaska Native (AI/AN) women currently have some of the highest mortality rates from breast cancer for any racial/ethnic group in the United States and some of the lowest screening rates. However, current data are not available for regional differences in screening, which can result in dramatically different stage at diagnosis and mortality. We conducted surveys with 120 focus group participants in a needs assessment of mammography among AI/AN in the greater Kansas City metropolitan area and parts of Northeast Kansas. We found that among women under age 40, for whom recommended screenings include only annual clinical breast examination and breast self-examination, more women reported breast self-examination than clinical breast examination (85.3% versus 55.0% in the past year). Among women age 40 and older, more women reported breast self-examination (80.0% in the past year) than either clinical breast examination or mammography (50.8% and 46.9%, respectively, in the past year). These low rates of breast cancer screening are consistent with low rates reported around the country among AI/AN and have strong implications for stage at diagnosis and prognosis for AI/AN breast cancer patients.

Breast cancer is the second leading cause of cancer mortality among American Indian and Alaska Native (AI/AN) women (US Department of Health and Human Services, 2002-2003), who have the lowest 5-year survival rates of all racial/ethnic groups (Clegg, Li, Hankey, Chu, and Edwards, 2002). AI/AN women are twice as likely to die from breast cancer than non-Hispanic white women (Li, Malone,

and Daling, 2003). Although incidence rates among AI/AN women are lower than for non-Hispanic white women (91.7/100,000 versus 123.5/100,000), more AI/AN women are diagnosed with late-stage breast cancers than other racial/ethnic groups, with 44% of newly diagnosed cases staged at regional or distant metastasis, compared to 33% among non-Hispanic whites (Smith-Bindman, et al., 2006; American Cancer Society, 2009-2010; Wampler, Lash, Silliman, and Heeren, 2005). Breast cancer incidence rates among AI/AN women differ by geographic region, with rates as high as 139.5/100,000 in Alaska and as low as 50.4/100,000 in the Southwest (Espey, et al., 2007). Recent data show that breast cancer incidence may be significantly under-reported among AI/AN women due, in large part, to racial misclassification (American Cancer Society, 2008).

Late stage at diagnosis and subsequently high mortality from breast cancer among AI/AN women are likely partially explained by low screening rates, particularly low rates of mammography that are declining (Espey, et al., 2007). Current breast cancer screening recommendations for average risk women age 40 and older are annual mammograms and clinical breast examination and monthly breast self-examination (American Cancer Society, 2007). Among AI/AN women age 40 and over, 62.7% report having had a mammogram in the past two years, compared to 68.7% among non-Hispanic whites (National Center for Health Statistics, 2007). Mammography rates also differ by geographic region, with rates lowest in the Pacific Coast (61.3%) and highest in the East (71.7%) (Espey, et al., 2007). In addition, AI/AN women living in urban areas (71.4%) are more likely to be screened than their rural or reservation counterparts (51.7%) (Schumacher, et al., 2008). Data detailing use of breast self-examination and clinical breast examination among AI/AN women are not reported in the literature.

Due to poor survival and screening rates and geographic variation in incidence, mortality, and screening rates, it is important to collect region-specific data concerning breast cancer screening behaviors. This study provides information about breast cancer screening behaviors among AI/AN women living in Northeast Kansas and the greater Kansas City metropolitan area in Kansas and Missouri.

METHOD

The data for these analyses came from a larger mixed-method needs assessment to determine needs and barriers to mammography among AI/AN. The surveys on which the data were based were conducted as a part of the focus group component of the study. The study protocols were approved by the institution's Human Subjects Committee prior to implementation of the study.

Focus group participants were recruited through listservs and mailing lists from partner organizations in the American Indian Health Research and Education Alliance, and through posters, flyers, and word-of-mouth at local cultural events, such as pow wows. Though both men and women were recruited into focus groups to discuss issues surrounding breast cancer, only data from women are reported here. Participants were eligible for this part of the study if they were 20 years of age and older and were of AI/AN descent. Written and verbal consent was obtained from each eligible participant. A total of 22 focus groups were conducted from 11/06/2007 thru 06/19/2008. Focus groups were stratified by gender; female focus groups were stratified by age (25-39 versus 40 and older), based on current recommendations for mammography for normal risk women, and screening status if age 40 or older (up-to-date with screening recommendations versus not up-to-date with screening recommendations). Women were considered up-to-date if they had a mammogram in the last two years. Participants were provided with a meal and a \$25 gift card for their time.

Prior to the start of each focus group, participants were invited to fill out a short survey asking about their breast cancer screening status as well as their knowledge about breast cancer, barriers to screening, and family history of breast cancer. For the purpose of these analyses, only surveys filled

out by female participants were included (N=120) and double data entered in a MS ACCESS database. Data entry comparisons and data analyses were performed using SAS. Discrete variables are described using frequencies and percentages while continuous variables are described using means and standard deviation. Bivariate analyses were performed using Chi-square for discrete outcomes and t-tests for continuous outcomes; significant differences were not found.

RESULTS

Table 1 provides basic demographic information obtained from 120 AI/AN women. Table 2 shows self-report breast cancer screening rates for the age categories of 20-39 and 40 and over. For the cohort aged 20-39 years, participants answered questions regarding clinical breast examination (N=49) and breast self-examination (N=47). The majority of women have had a clinical breast examination (83.7%) and more than half of these women had one within the year (55.0%). The explanation provided for most recent clinical breast examination was due to a routine women's health exam (92.9%). The remaining respondents claimed their most recent clinical breast examination took place due to symptoms or a recommended follow-up visit. Almost three-fourths of respondents have performed breast self-examination (72.3%), 85.3% of those within the year.

Table 1: Demographics of the AI/AN sample for breast cancer screening (N=120)

	N	%
Age (mean,std)	45.5	13.3
Race		
American Indian/Alaska Native	100	83.3
Multi-racial	20	16.7
Marital Status		
Married/Partner	54	45.0
Divorced/Widowed	46	38.3
Never Married	20	16.7
Education		
High school or less	24	20.2
Some college	45	37.8
College +	50	42.0
Health insurance*		
No	34	28.3
Yes	86	71.7
Health care received at		
IHS	56	47.9
Other facility	61	52.1
Discussed Breast cancer screening		
No	38	33.9
Yes	74	66.1

* In addition to IHS

Table 2: Self-report breast cancer screening practices

	20-39 years old (N=49)		40+ years old (N=71)	
	N	%	N	%
Discussed Breast cancer screening				
No	NA	NA	12	18.5
Yes	NA	NA	53	81.5
Most recent mammogram				
Year or less	NA	NA	31	43.7
1 - 5 years	NA	NA	32	45.1
5+ years	NA	NA	3	4.2
Never had a mammogram	NA	NA	5	7.0
Reason for most recent mammogram				
Routine exam	NA	NA	61	92.4
Symptom/Follow-up	NA	NA	4	6.0
Unknown	NA	NA	1	1.5
Mammogram frequency				
Every year	NA	NA	34	47.9
Every other year	NA	NA	13	18.3
Irregularly	NA	NA	13	18.3
Only 1 mammogram	NA	NA	7	9.9
Never had a mammogram	NA	NA	5	7.0
Ever had a Clinical Breast Examination				
No	8	16.3	6	8.8
Yes	41	83.7	62	91.2
Most recent Clinical Breast Examination				
Year or less	22	55.0	31	50.8
1 -5 years	13	32.5	25	41.0
5+ years	5	12.5	5	8.2
Reason for most recent Clinical Breast Examination				
Routine exam	38	92.9	52	89.7
Symptom/Follow-up	3	7.3	6	10.3
Ever done Breast Self-Examination				
No	13	27.7	9	13.0
Yes	34	72.3	60	87.0
Most recent Breast Self-Examination				
Month or less	9	26.5	24	40.0
1 month - 1 year	20	58.8	24	40.0
1 - 5 years	3	8.8	7	11.7
5+ years	2	5.9	5	8.3

Self-reported breast cancer screening rates for women who were aged 40 years and over (N=71) are also included in Table 2. Participants answered questions regarding mammograms, clinical breast examination, and breast self-examination. The majority of respondents (81.5%) had discussed mammography with a health professional; 43.7% had a mammogram within the last year. The reason given for most recent mammogram was a routine exam. For those who have had a mammogram, half reported a yearly mammogram while one-fifth reported a mammogram every other year.

For those women who had a clinical breast examination (91.2%), half had one in the past year. Eighty-seven percent of participants had performed breast self-examination and of those, 80% had done so within the year.

DISCUSSION

These data indicate that women aged 20-39 years are more likely to have performed breast self-examination than to have had a clinical breast examination within one year or less and women aged 40 and over are more likely to have performed breast self-examination in the last year than to have had a clinical breast examination or a mammogram. The difference in use of screening modalities may be due to the fact that women can complete breast self-examination without a provider. We have learned from our larger study that women sometimes avoid going to providers due to mistrust issues or gender issues (Daley, Joseph, Monteau, Cully, and Kraemer-Diaz, 2010), showing that it is possible that women are more comfortable screening themselves than trusting a provider, particularly a male provider. It is also possible that women did not understand what a clinical breast examination entailed and were under-reporting their use. Additionally, women may have over-reported use of breast self-examination due to media campaigns for the technique, though studies fail to show any improved survival from performance (Hackshaw and Paul, 2003; Irwin, Artin, and Oxman, 1999; Kusters and Gotzsche, 2003). Other issues that may explain this difference in use of screening techniques are lack of knowledge about screening modalities and cultural barriers. Further exploration into reasons for disparities in screening modality is needed.

Mammography is considered the gold standard for breast cancer screening and is recommended for average risk women annually beginning at age 40 (American Cancer Society, 2008). 66.2% of the women in our sample reported annual or bi-annual mammography, indicating that a similar percentage of age-eligible AI/AN women in our sample were up-to-date with screening compared to the national average for AI/AN (66.6%, American Cancer Society, 2009-2010). Mammography rates for AI/AN in our sample, like rates for other AI/AN around the country, lag behind those for non-Hispanic whites (68.1%, American Cancer Society, 2009-2010). It is possible that self-selection into our study biased our sample and our screening rates are not indicative of the overall screening rates of women in our greater population. If there is selection bias in our sample, it is likely that our sample had more women who are up-to-date with screening recommendations than are represented in the general AI/AN community in Kansas and Missouri. Therefore, it is possible that AI/AN in our region lag behind other AI/AN around the nation in screening mammography rates. Because of our small sample size, we cannot generalize screening rates to the population level. Therefore, screening rates may be lower than the current data suggest. Preliminary results from our focus group data indicate that cost of the test, fear of the test and the potential results of the test, transportation, and access to care or lack of insurance are all major barriers.

Fifty-three of our respondents indicated that they had discussed breast cancer screening with a health professional, but 66 respondents reported having had a mammogram. It is likely that the 66 women who had a mammogram discussed breast cancer screening with a health professional. A possible explanation for this difference may be the perceived quality of health education given

by health care professionals to AI/AN women. In addition, the data rely on women's memory of the screening process.

Our data show that AI/AN women in the Heartland lag behind other women in the United States in breast cancer screening behaviors. Low rates of screening have important implications for stage at diagnosis of breast cancer, putting the women in our sample at greater risk for late stage diagnosis, similar to other AI/AN communities around the country. Barriers to screening are now being studied and should allow the development of culturally-appropriate screening interventions to decrease the disparity in screening rates and ultimately decrease diagnosis of late-stage breast cancer among AI/AN.

REFERENCES

- American Cancer Society. (2008). *Cancer Facts & Figures 2008*. Atlanta.
- American Cancer Society. (2009-2010). *Breast cancer facts and figures 2009-2010*. American Cancer Society. Atlanta.
- Clegg, L. X., Li, F. P., Hankey, B. F., Chu, K., and Edwards, B. K. (2002). Cancer survival among US whites and minorities: a SEER (Surveillance, Epidemiology, and End Results) Program population-based study. *Arch Intern Med*, 162(17), 1985-1993.
- Daley, C., Joseph, S., Monteau, D., Cully, A., and Kraemer-Diaz, A. (2010). Barriers to mammography among Native women in Kansas and Missouri. Spirit of Eagles 8th National Changing Patterns of Cancer in Native Communities. Seattle, WA.
- Espey, D. K., Wu, X. C., Swan, J., Wiggins, C., Jim, M. A., Ward, E., et al. (2007). Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. *Cancer*, 110(10), 2119-2152.
- Hackshaw, A. K., and Paul, E. A. (2003). Breast self-examination and death from breast cancer: a meta-analysis. *Br J Cancer*, 88(7), 1047-1053.
- Irwin, M., Artin, K.H., and Oxman, M.N. (1999). Screening for depression in the older adult: criterion validity of the 10 item center for epidemiological studies depression scale (CES-D). *Archives of Internal Medicine*, 159, 1701-1704.
- Kosters, J. P., and Gotzsche, P. C. (2003). Regular self-examination or clinical examination for early detection of breast cancer. *Cochrane Database Syst Rev*(2), CD003373.
- Li, C. I., Malone, K. E., and Daling, J. R. (2003). Differences in breast cancer stage, treatment, and survival by race and ethnicity. *Arch Intern Med*, 163(1), 49-56.
- National Center for Health Statistics. (2007). *Health, United States, 2007 with Chartbook on Trends in the Health of Americans*. Hyattsville, MD: U.S. Department of Health and Human Services
- Schumacher, M. C., Slattery, M. L., Lanier, A. P., Ma, K. N., Edwards, S., Ferucci, E. D., et al. (2008). Prevalence and predictors of cancer screening among American Indian and Alaska native people: the EARTH study. *Cancer Causes Control*, 19(7), 725-737.
- Smith-Bindman, R., Miglioretti, D. L., Lurie, N., Abraham, L., Barbash, R. B., Strzelczyk, J., et al. (2006). Does utilization of screening mammography explain racial and ethnic differences in breast cancer? *Ann Intern Med*, 144(8), 541-553.
- US Department of Health and Human Services. (2002-2003). *IHS. Trends in Indian Health*. Washington, DC: U.S. Department of Health and Human Services.
- Wampler, N. S., Lash, T. L., Silliman, R. A., and Heeren, T. C. (2005). Breast cancer survival of American Indian/Alaska Native women, 1973-1996. *Soc Prev Med*, 50(4), 230-237.

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