Title

Self-Report Versus Medical Record for Mammography Screening Among Minority Women

Journal

Western Journal of Nursing Research, 38(12)

ISSN

0193-9459

Authors

Nandy, Karabi
Menon, Usha
Szalacha, Laura A
et al.

Publication Date

2016-12-01

DOI

10.1177/0193945916647059

Peer reviewed

Western Journal of Nursing Research
2016, Vol. 38(12) 1627–1638

DOI: 10.1177/0193945916647059
wjn.sagepub.com
SAGE

Self-Report Versus Medical Record for Mammography Screening Among Minority Women

Karabi Nandy[1], Usha Menon[2], Laura A. Szalacha[2], HanJong Park[3], Jongwon Lee[4], and Eunice E. Lee[1]

Abstract

Self-report is the most common means of obtaining mammography screening data. The purpose of this study was to assess the accuracy of minority women's self-reported mammography by comparing their self-reported dates of mammograms with those in their medical records from a community-based randomized control trial. We found that out of 192 women, 116 signed the Health Information Portability and Accountability Act form and, among these, 97 had medical records that could be verified (97 / 116 = 83.6%). Ninety-two records matched where both sources confirmed a mammogram; 48 of 92 (52.2%) matched perfectly on self-reported date of mammogram. Complexities in the verification process warrant caution when verifying self-reported mammography screening in minority populations. In spite of some limitations, our findings support the usage of self-reported data on mammography as a validated tool for other researchers investigating mammography screening among minority women who continue to have low screening rates.

[1]University of California, Los Angeles, CA, USA
[2]University of Arizona College of Nursing, Tucson, AZ, USA
[3]Kyung Hee University, Seoul, South Korea
[4]University of New Mexico, Albuquerque, NM, USA

Corresponding Author:
Karabi Nandy, School of Nursing and School of Public Health, University of California, 700 Tiverton Ave, Los Angeles, CA 90095, USA.
Email: knandy@sonnet.ucla.edu

Keywords
mammography, self-report, medical records, breast cancer screening, validation

Accurate reporting of cancer screening behaviors is crucial for public health surveillance and preventive efforts. Findings can differ depending on whether the data come from self-report or medical record. Although self-report is an easy and cost-effective method for collecting data on health behaviors, under or over-reporting can bias estimates. However, medical records provide accurate data, but the cost of doing medical record reviews on large samples is prohibitive. Few studies have examined the validity of self-reported mammography in community-based intervention studies that took place outside of clinics or hospitals and none with Korean Americans (KAs).

Mammography Screening Among KAs

Breast cancer is the most commonly occurring cancer and the most common cause of cancer mortality among KA women in the United States (Miller, Chu, Hankey, & Ries, 2008). Mammography is considered the gold standard for early detection of breast cancer (Parkin, Bray, Ferlay, & Pisani, 2005). Mammography rates among KA women, however, are lower than are those among Caucasian women and other ethnic minority groups (Kagawa-Singer & Pourat, 2000; Ryu, Crespi, & Maxwell, 2013). This leads to late-stage diagnosis in this population, which results in increased morbidity and mortality (Miller, Hankey, & Thomas, 2002). Efforts to increase screening, particularly with a culturally appropriate intervention continue to be a priority in racial/ethnic minority populations.

Previous studies have evaluated mammography screening for racial/ethnic minority women. The targeted behavioral changes are usually measured through either self-report (Eun, Lee, Kim, & Fogg, 2009; Han, Lee, Kim, & Kim, 2009; Jandorf et al., 2008) or more objective methods, such as direct observation or medical record review (Ferrante et al., 2008). In community settings, self-report is the most common source of data for cancer screening studies. Unfortunately, self-reported data can be under- or over-reported due to the bias of respondents' recall, lack of understanding of the questions asked, and/or responses based on social desirability (Newell, Girgis, Sanson-Fisher, & Savolainen, 1999).

Surveys such as the National Health Interview Survey (NHIS) and Behavioral Risk Factor Surveillance System (BRFSS) provide mammography usage data at the county, state, and national levels that are often used to

inform health policies (Block, Jarlenski, Wu, & Bennett, 2013; Pace, He, & Keating, 2013). Mammography rates from both the NHIS and BRFSS, assessed by self-report, lead to over-estimated screening numbers, and the amount of over-estimation may vary by demographic characteristics (Cronin et al., 2009).

Past studies of self-reports of mammography screening suggest that mammograms tend to be over-reported among all populations (Howard, Agarwal, & Lytwyn, 2009). According to Medicare claims data, race, education, income, insurance, and health status all affect verifiable mammography (Holt, Franks, Meldrum, & Fiscella, 2006). Over-reporting of mammography was found in Hispanic and African American women (Allgood, Rauscher, Whitman, Vasquez-Jones, & Shah, 2014; Champion, Menon, McQuillen, & Scott, 1998; Mojica & Bastani, 2010; Powe & Cooper, 2008; Tumiel-Berhalter, Finney, & Jaén, 2004). In one study, it was suggested that when using self-reported mammography data for low-income, ethnic minority women, self-reports should be adjusted downward by as much as one quarter to one third (McPhee et al., 2002).

In general, medical records are considered a comprehensive source of health data. However, reviewing medical records can take much time and effort, and the quality of medical records can vary (Ferrante et al., 2008; Tisnado et al., 2007). Also, some women obtain mammograms from health fairs and other mobile sources that might not be integrated into their medical record. Such medical records may not be an accurate source of data for tracking mammography screening in a community sample, particularly among minority populations such as KAs.

To further complicate the issue, obtaining information about mammography uptake is classified as protected health information under the Health Information Portability and Accountability Act (HIPAA; Centers for Disease Control and Prevention [CDC], 2003). Therefore, researchers must obtain written consent with detailed information, such as the name of a specific health care provider or agency to contact for the release of protected health information, the purpose of the request, and a finite duration for use of their data from study participants, which is often difficult to obtain (CDC, 2003). When studies are clinic or hospital based, HIPAA consent forms can be completed with relative ease because the health care provider and study participant information is readily available. When studies are community based, each participant has to inform research personnel about where they would or did obtain a mammogram, and each provider must be contacted individually. Because a relatively higher percentage of minority women are uninsured and lack a consistent primary health care provider, obtaining this information on the consent form at the start of the study can be quite challenging.

Purpose

Our goal was to assess the accuracy of self-reported mammography, compared with medical record data among KA women who participated in a community-based randomized controlled trial (RCT), Korean Immigrants and Mammography–Culture-Specific Health Intervention (KIM-CHI; Lee et al., 2014), a program focused on changing KA women's culture-specific beliefs about breast cancer and mammograms and improving spousal support for screening. The concordance between the two data sources provides information about the accuracy of self-reported mammography among KA women.

Method

Participants were recruited from 50 religious organizations in a large Midwestern city with institutional review board approval from the parent university as part of the KIM-CHI study. The goal of KIM-CHI was to increase mammography uptake among KA women. Of the total sample, 211 women were in the intervention group (educated about breast cancer and cancer screening), and 217 women were in the control group (educated about healthy diet). All the participants were non-adherent to breast cancer screening at baseline, meaning that they had not had a mammogram within the past 12 months prior to study participation. Although husbands and wives both participated in the study, only the women's self-reports were collected and included herein. Results of the parent study are reported elsewhere (Lee et al., 2014). The participants ($N = 394$; 194 women in the intervention group and 200 in the control group) were interviewed via phone at 15 months post-baseline and asked whether they had had a mammogram during the study period. Women who reported having had a mammogram during the study period were asked to sign on HIPAA consent, and then the accuracy of self-reported mammography was verified by comparing their self-reported mammography dates with those found in their medical records. Each participant was given a US$20 gift card as an incentive for returning the signed HIPAA form. The data from the medical records of these women were then compared with their self-reported data. The two sources of data were considered a match as long as both confirmed a mammogram. Up to 3 months' discrepancy in dates was accepted as a match between sources.

Results

Of the 394 KA women who started out in the study, 192 (48.7%) reported having had at least one mammogram at 15 months since baseline. Characteristics

of the 192 women in the study sample are as follows: the mean age of the sample was 54.19 years, ranging from 40 to 74 years; 59% had education at high school level or more and 44% had annual income greater than US$40,000. Fifty-six percent had health insurance and 71% had access to health care and 20% reported a history of breast cancer in their families.

Sources of Verification

All the mammography facilities ($n = 54$, 59%), health care providers' offices ($n = 26$, 28%), and community service centers ($n = 12$, 13%) released patient health information (PHI) we requested after we faxed them the HIPAA release form regarding each woman's mammogram uptake history within the study period. We did not collect information about the results of the mammograms.

Self-Report Versus Medical Record

The 192 women were asked via telephone if they would sign the HIPAA consent forms to give the research team access to their medical records; 181 (94.3%) consented. HIPAA forms were mailed to the women who agreed to sign the forms, requesting information about where they obtained the mammogram and the names and addresses of their physicians or mammogram facility. Of the 181 women who agreed to sign the HIPAA consent forms, 116 actually signed and mailed them back to the research team. Among those who returned the form, 19 mammograms were not verifiable (11 women reportedly obtained their mammograms in Korea, and 8 women did not provide the correct name of their medical facility; Figure 1). Of the remaining 97 women, we were able to verify 92 self-reported mammograms. Of the 92 self-reports that matched the medical records, 48 were exact matches for the reported date of the mammogram, 30 were well matched (≤1 month difference), and 14 (15.2%) matched with a difference of greater than 1 month but less than 3 months between the two sources (Figure 1).

We noted that the median age of the 181 women who agreed by signing HIPAA consent was 54.17 years (Interquartile Range [IQR] = 16) compared with 50 years (IQR = 8) for the 11 women who did not sign HIPAA consent ($p = .49$ from a non-parametric Wilcoxon Rank Sum Test). Similarly, the median age of the 116 women who signed and returned HIPAA consent forms was 54 years (IQR = 16) compared with 51.5 years (IQR = 14) for the 76 women who did not ($p = .08$ from a non-parametric Wilcoxon Rank Sum Test). These data indicate that age was not significantly related to the HIPAA consent rate or HIPAA return rate.

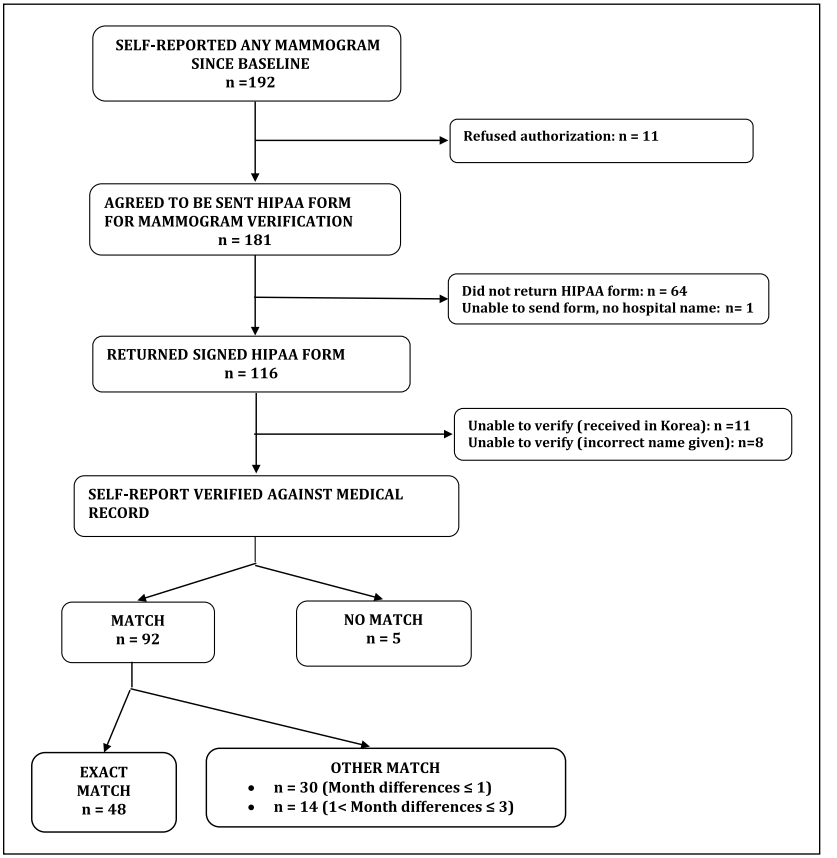

Figure 1. Flow diagram showing verification of self-reports of mammography to medical records in the KIM-CHI study.
Note. KIM-CHI = Korean Immigrants and Mammography–Culture-Specific Health Intervention; HIPAA = Health Information Portability and Accountability Act.

We also note that the methodology of the original RCT did not influence the sample of this study in any way. We found that at 15 months, 54.3% (n = 63) of KA women in the intervention group signed HIPAA consent forms compared with 45.7% (n = 53) in the control group, not statistically different (p = .64). Similarly, we found that there was no statistical difference between intervention and control groups with regard to the proportion of KA women whose self-reported dates of mammography matched those in their medical records (56.5%, n = 52 vs. 43.5%, n = 40; p = .37). As such, with regard to

comparisons between self-reports and medical records on mammography, our findings are not influenced by the goals of the original study.

Discussion

To the best of our knowledge, this is the first validation of self-reported mammography with medical records in KA women in community settings. We were unable to calculate the sensitivity and specificity of the verification because a relatively high percentage of women in our study did not have health insurance (32%), a regular home for medical care (28.7%), or a primary care physician (29%) to verify whether those women who reported that they did not have a mammogram during the study period actually did not obtain one. Thus, we focused on reporting the matched rate between self-reported and medical record data.

Our goal was to assess the accuracy of self-reported mammography in our sample of KA women. Of the 116 women who returned their signed HIPAA forms giving us permission to check their medical records, we were able to track down the medical records of 92; thus, our verification rate was nearly 80% (92 / 116) of self-reported mammograms. This is similar to, or slightly higher than, the findings from other studies with Hispanics and African Americans (48%-79% verification rates; Allgood et al., 2014; Champion et al., 1998; McPhee et al., 2002). When the 11 women who obtained a mammogram in Korea were included, the verification rate rose from 80% to 88%. However, based on the 192 self-reported mammograms, fewer than half were verifiable (92 / 192 = 47.9%) because only 60% returned signed HIPAA consents. Another study found the return rate of signed consent forms to be 50% with similar incentives for participants (Bolcic-Jankovic, Clarridge, Fowler, & Weissman, 2007). Incentivizing participants for consent is standard practice in community-based studies. Therefore, we expect that it is more the nature of HIPAA forms that influence HIPAA return rates than incentives for participants.

In general, obtaining HIPAA consent when conducting research studies can be problematic. Only 50.3% of participants returned signed HIPAA authorization forms after being discharged from hospitals in a study measuring common characteristics of research participants (Ness, 2007). Requesting social security numbers and not having clear information about their hospital/health care center may have influenced the low rate of return. We speculate that some women in our study were reluctant to return the authorization form because they were not sure of the name of the primary care provider who ordered the mammogram, or they lacked full information about the mammography facility. Furthermore, ethnic minority women's lack of an

established place of care—a primary care physician or regular place to act on mammogram referrals—makes it extremely difficult to obtain medical record data. Prior to initiating the intervention study, we could have collaborated with community resources for KAs more actively to obtain routine mammograms, so that during the study period, those women who did not have a regular place to obtain mammograms could be referred to the community resources. In the RCT, we collaborated with one of the largest KA community agencies in the area to refer study participants to low-cost or free mammograms, and 12 mammograms were verified through this agency. One important lesson learned was that we could have added several more such agencies in the area for the study participants' convenient access.

Obtaining data from medical records, which are considered more reliable than self-report, presents problems related to target populations. Most intervention studies aimed at mammography uptake target marginalized, minority populations where the needs are the greatest. These populations generally have low incomes, low health literacy, lack knowledge about diseases, lack adequate health insurance coverage, and do not usually have an established place for a regular source of care (Alexandraki & Mooradian, 2010; Lee, Fogg, & Sadler, 2006). Low health literacy poses an obstacle to obtaining signed HIPAA consents because these forms are often written at higher literacy levels. In addition, there are issues of trust related to giving health researchers' access to health records (Stewart, 2007).

Even if we had obtained HIPAA consent at baseline during the study, about 30% of KA women would not have been able to fill out the health care provider information on the HIPAA form because they did not have a regular source of care and/or primary health care provider to refer them for mammograms.

Even if women have a fixed place of care, they may not be obtaining cancer screenings at those places because of the availability of low- or no-cost mammography outside of typical health care facilities. Some state and local health programs provide mammograms free or at low cost. The CDC (2003) coordinates the National Breast and Cervical Cancer Early Detection Program. Information about free or low-cost mammography screening programs is also available from the National Cancer Institute's Cancer Information Service, Susan G. Komen for the Cure, Young Women's Christian Association, and National Breast and Cervical Cancer Control Program. When women obtain mammograms from these sources, the information does not necessarily get translated into their medical records. Therefore, the use of medical records as a source of screening data is fraught with these limitations.

In relation to the 11 women in our study who had mammograms in Korea, a focus group discussion found that an increasing number of KAs

use health services in Korea because of the lower cost and convenience, good quality of care, and use of the Korean language in the health care setting (Oh, Jun, Zhou, & Kreps, 2014). In Korea, KAs can obtain various screening procedures in one place at more affordable prices than in the United States. However, there are challenges with continuity of care, especially with abnormal findings, for KAs who receive health care services in Korea. As such, KAs who are screened in Korea should receive education about obtaining some kind of documentation in English, preferably electronically, about the results of the screening so that they can receive follow-up care in the United States, if necessary. This is typically not a problem for women screened in the United States because in case of positive test results, they are usually recommended for further testing. The inclusion of care coordination and navigation type programs across many clinics in the country leads to women being guided through the next steps of diagnostic testing and treatment.

We recognize that those women who had knowingly inaccurately reported their mammogram history would be less likely to consent to verifying their mammogram record. Therefore, our assessment of reporting accuracy could be biased to some unknown degree because women who did not have a mammogram may not have consented to the medical record verification.

Cancer screening interventions must move from efficacy trials to dissemination and translation, for maximum reach and impact, by going directly into communities and applying study findings to the improvement of the community's health. However, it is neither feasible nor cost-effective to obtain cancer screening data through any means other than self-report. Our results indicate that there is high accuracy in self-reported breast cancer screening among KA women who returned signed HIPAA consent forms. Therefore, our findings support the usage of self-reported data on mammography as a validated tool for other researchers investigating mammography screening among KA women who continue to have low screening rates.

Acknowledgments

We gratefully acknowledge the Korean American couples who consented to participate in the study and the leaders of the multiple Korean religious organizations where we collected the data.

Authors' Note

The data collection for this study was conducted by the last/senior author while at the University of Illinois–Chicago College of Nursing. This study was approved by the institutional review boards of the University of Illinois at Chicago and University of California, Los Angeles.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by a grant from the National Cancer Institute (R01CA127650).

References

Alexandraki, I., & Mooradian, A. D. (2010). Barriers related to mammography use for breast cancer screening among minority women. *Journal of the National Medical Association*, *102*, 206-218. doi:10.1016/S0027-9684(15)30527-7

Allgood, K. L., Rauscher, G. H., Whitman, S., Vasquez-Jones, G., & Shah, A. M. (2014). Validating self-reported mammography use in vulnerable communities: Findings and recommendations. *Cancer Epidemiology, Biomarkers & Prevention*, *23*, 1649-1658. doi:10.1158/1055-9965.EPI-13-125

Block, L. D., Jarlenski, M. P., Wu, A. W., & Bennett, W. L. (2013). Mammography use among women ages 40-49 after the 2009 U.S. Preventive Services Task Force recommendation. *Journal of General Internal Medicine*, *28*, 1447-1453. doi:10.1007/s11606-013-2482-5

Bolcic-Jankovic, D., Clarridge, B. R., Fowler, F. J., & Weissman, J. S. (2007). Do characteristics of HIPAA consent forms affect the response rate? *Medical Care*, *45*, 100-103. doi:10.1097/01.mlr.0000241062.79855.35

Centers for Disease Control and Prevention. (2003). HIPAA Privacy Rule and public health: Guidance from CDC and the U.S. Department of Health and Human Services. *Morbidity and Mortality Weekly Report*, *52*(Suppl.), 1-20.

Champion, V. L., Menon, U., McQuillen, D. H., & Scott, C. (1998). Validity of self-reported mammography in low-income African-American women. *American Journal of Preventive Medicine*, *14*, 111-117.

Cronin, K. A., Miglioretti, D. L., Krapcho, M., Yu, B., Geller, B. M., Carney, P. A., & Ballard-Barbash, R. (2009). Bias associated with self-report of prior screening mammography. *Cancer Epidemiology, Biomarkers & Prevention*, *18*, 1699-1705. doi:10.1158/1055-9965.EPI-09-0020

Eun, Y., Lee, E. E., Kim, M. J., & Fogg, L. (2009). Breast cancer screening beliefs among older Korean American women. *Journal of Gerontological Nursing*, *35*, 40-50. doi:10.3928/00989134-20090731-09

Ferrante, J. M., Ohman-Strickland, P., Hahn, K. A., Hudon, S. V., Shaw, E. K., Crosson, J. C., & Crabtree, B. F. (2008). Self-report versus medical records for assessing cancer-preventive services delivery. *Cancer Epidemiology, Biomarkers & Prevention*, *17*, 2987-2994.

Han, H.-R., Lee, H., Kim, M. T., & Kim, K. B. (2009). Tailored lay health worker intervention improves breast cancer screening outcomes in nonadherent

Korean-American women. *Health Education Research*, *24*, 318-329. doi:10.1093/her/cyn021

Holt, K., Franks, P., Meldrum, S., & Fiscella, K. (2006). Mammography self-report and mammography claims: Racial, ethnic, and socioeconomic discrepancies among elderly women. *Medical Care*, *44*, 513-518.

Howard, M., Agarwal, G., & Lytwyn, A. (2009). Accuracy of self-reports of Pap and mammography screening compared to medical record: A meta-analysis. *Cancer Causes & Control*, *20*, 1-13. doi:10.1007/s10552-008-9228-4

Jandorf, L., Bursac, Z., Pulley, L., Trevino, M., Castillo, A., & Erwin, D. O. (2008). Breast and cervical cancer screening among Latinas attending culturally specific educational programs. *Progress in Community Health Partnerships*, *2*, 195-204. doi:10.1353/cpr.0.0034

Kagawa-Singer, M., & Pourat, N. (2000). Asian American and Pacific Islander breast and cervical carcinoma screening rates and healthy people 2000 objectives. *Cancer*, *89*, 696-705.

Lee, E. E., Fogg, L. F., & Sadler, G. (2006). Factors of breast cancer screening among Korean immigrants in the United States. *Journal of Immigrant and Minority Health*, *8*, 223-233. doi:10.1007/s10903-006-9326-2

Lee, E. E., Menon, U., Nandy, K., Szalacha, L., Kviz, F., Cho, Y., & Park, H. (2014). The effect of a couples' intervention to increase breast cancer screening among Korean Americans. *Oncology Nursing Forum*, *41*, E185-E193. doi:10.1188/14.ONF.E185-E193

McPhee, S. J., Nguyen, T. T., Shema, S. J., Nguyen, B., Somkin, C., Vo, P., & Pasick, R. (2002). Validation of recall of breast and cervical cancer screening by women in an ethnically diverse population. *Preventive Medicine*, *35*, 463-473.

Miller, B. A., Chu, K. C., Hankey, B. F., & Ries, L. A. G. (2008). Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S. *Cancer Causes Control*, *19*, 227-256. doi:10.1007/s10552-007-9088-3

Miller, B. A., Hankey, B. F., & Thomas, T. L. (2002). Impact of sociodemographic factors, hormone receptor status, and tumor grade on ethnic differences in tumor stage and size for breast cancer in US women. *American Journal of Epidemiology*, *155*, 534-545.

Mojica, C. M., & Bastani, R. (2010). Receipt of diagnostic tests for breast cancer: Validity of self-reports among low-income, mostly Latina, indigent women. *Evaluation & the Health Professions*, *33*, 437-456. doi:10.1177/0163278710367802

Ness, R. B. (2007). Influence of the HIPAA Privacy Rule on health research. *Journal of the American Medical Association*, *298*, 2164-2170. doi:10.1001/jama.298.18.2164

Newell, S. A., Girgis, A., Sanson-Fisher, R. W., & Savolainen, N. J. (1999). The accuracy of self-reported health behaviors and risk factors relating to cancer and cardiovascular disease in the general population: A critical review. *American Journal of Preventive Medicine*, *17*, 211-229.

Oh, K. M., Jun, J., Zhou, Q., & Kreps, G. (2014). Korean American women's perceptions about physical examinations and cancer screening services offered in

Korea: The influences of medical tourism on Korean Americans. *Journal of Community Health*, *39*, 221-229. doi:10.1007/s10900-013-9800-z

Pace, L. E., He, Y., & Keating, N. L. (2013). Trends in mammography screening rates after publication of the 2009 US Preventive Services Task Force recommendations. *Cancer*, *119*, 2518-2523. doi:10.1002/cncr.28105

Parkin, D. M., Bray, F., Ferlay, J., & Pisani, P. (2005). Global cancer statistics. *CA: A Cancer Journal for Clinicians*, *55*, 74-108.

Powe, B. D., & Cooper, D. L. (2008). Self-reported cancer screening rates versus medical record documentation: Incongruence, specificity, and sensitivity for African American women. *Oncology Nursing Forum*, *35*, 199-204. doi:10.1188/08.ONF.199-204

Ryu, S. Y., Crespi, C. M., & Maxwell, A. E. (2013). What factors explain disparities in mammography rates among Asian American immigrant women? A population-based study in California. *Women's Health Issues*, *23*, e403-e410. doi:10.1016/j.whi.2013.08.005

Stewart, R. S. (2007). Protective measures for private health information. *Perspectives in Health Information Management*, *4*, 5.

Tisnado, D. M., Adams, J. L., Liu, H., Damberg, C. L., Hu, A., Chen, W. P., & Kahn, K. L. (2007). Does concordance between data sources vary by medical organization type? *American Journal of Managed Care*, *13*, 289-296.

Tumiel-Berhalter, L. M., Finney, M. F., & Jaén, C. R. (2004). Self-report and primary care medical record documentation of mammography and Pap smear utilization among low-income women. *Journal of the National Medical Association*, *96*, 1632-1639.