

Self-Reported Cancer Screening Rates Versus Medical Record Documentation: Incongruence, Specificity, and Sensitivity for African American Women

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Purpose/Objectives: To evaluate levels of incongruence, specificity, and sensitivity between self-reported screening and medical record documentation for breast, cervical, and colorectal cancer screening.

Design: Descriptive, quantitative.

Setting: Federally qualified health centers in the southeastern United States.

Sample: 116 African American women. The mean age was 35 years, and the mean educational level was 12.6 years.

Methods: Women were eligible to participate in the study if they were older than age 18 and able to understand English or Spanish. They were recruited from the waiting areas of health centers over a consecutive five-day period.

Main Research Variables: Self-reported rates of screening and screening rates documented in the medical record.

Findings: The level of incongruence between self-report and medical record documentation was more than 50% for some procedures. Rates of specificity were high, particularly over time. Rates of sensitivity were 33% or less.

Conclusions: The women tended to overreport screenings in the past year when compared to medical records. The women and medical records indicated that the screenings had not been performed in the past two to five years or more than five years ago.

Implications for Nursing: Nurses are in a unique position to educate women about cancer screening in a culturally and educationally appropriate way while ensuring that those conversations and procedures are documented in the medical record by all providers.

Key Points . . .

- Low-income African American women had low rates of breast and colorectal cancer screening.
- Self-reported cancer screening rates were incongruent with those documented in the medical record.
- Incongruence between the self-report and medical record documentation may lead to missed cancer screening opportunities.

tor in decreasing cancer mortality rates; however, the literature suggests that African Americans are less likely than others to participate in cancer screening and early detection programs (Champion et al., 2006; Champion et al., 2003; Champion & Menon, 1997; Powe, 1995; Russell, Monahan, Wagle, & Champion, 2007; Skinner, Champion, Menon, & Seshadri, 2002; Trauth et al., 2005; Weinrich, Weinrich, Atwood, Boyd, & Greene, 1998).

Statistics used to determine rates of participation in cancer screening typically are based on patients' self-reported screening or medical records. Medical records are viewed by some as the gold standard and are the legal standard by which care is documented and evaluated. Although self-reports are a key component of patients' health histories, their reliability and accuracy often are debated. Even so, population-based studies (e.g., Behavioral Risk Factor Surveillance Survey, National Health and Nutritional Examination Survey) have influenced policy and reported on national trends based on self-reported screening, which may be over- or underestimated by patients when compared to medical records. Over- or underestimation of screening can be even more significant for African Americans, who bear a disproportionate cancer burden.

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African Americans continue to experience higher cancer incidence (all sites combined), higher mortality rates, and lower rates of cancer survival than other racial and ethnic groups in the United States (American Cancer Society, 2007a). Despite having a lower incidence of breast cancer compared to Caucasian women older than age 40, African American women have a higher mortality rate from the disease. Furthermore, for women younger than age 40, the incidence of breast cancer actually is higher among African Americans than Caucasians (American Cancer Society, 2007b). The same trend is evident in other cancers; the incidence and mortality rates for colorectal cancer for African Americans far exceed those of Caucasians, and the mortality rate for cervical cancer in African American women is almost double the rate of Caucasian women (National Cancer Institute, 2007). Early detection followed by effective treatment is believed to be a crucial fac-

Research that compared self-reported screening to medical record documentation found that the patients overestimated their participation in mammography (Champion, Menon, McQuillen, & Scott, 1998), clinical breast examination (CBE) (Whitman et al., 1994), cervical cancer screening (Fiscella, Holt, Meldrum, & Franks, 2006; Fowles, Fowler, Craft, & McCoy, 1997; Whitman et al.), and colorectal cancer screening (Gordon, Hiatt, & Lampert, 1993; Hall et al., 2004). Hoyo, Ostbye, Skinner, Yarnall, and Chowdhary (2005) and Tumiel-Berhalter, Finney, and Jaen (2004) reported that African Americans may have a higher percentage of disagreement between their self-reported screening and medical records compared to Caucasians, but African American women with higher incomes and education were more likely to have consistent agreement between self-reported Pap testing and documentation in medical records. Other research suggested that African American patients can accurately recall whether they have been screened but are less accurate in determining the time interval of the screening (Caplan et al., 2003; Mandelson, LaCroix, Anderson, Nadel, & Lee, 1999; Matthews, Nattinger, & Anderson, 2005; McGovern, Lurie, Margolis, & Slater, 1998; Montano & Phillips, 1995; Paskett et al., 1996; Vacek, Mickey, & Worden, 1997; Zapka et al., 1996) and may overestimate the frequency of Pap testing if they have had other gynecologic procedures (Pizarro, Schneider, & Salovey, 2002).

Relatively few recent studies have addressed the issue of self-reported cancer screening among African Americans. Therefore, the current study adds to the science by assessing the incongruence, specificity, and sensitivity (see Figure 1) for breast (CBE, mammography), cervical (Pap testing), and colorectal cancer (fecal occult blood test [FOBT]) screening among African American women who attend federally qualified health centers (FQHC) in the southeastern United States. Accurate information about participation in cancer screening, whether from self-report or the medical record, is vital to assess cancer control efforts, such as developing educational strategies, making purchasing decisions, and ensuring adequate numbers of providers to meet the healthcare needs of this population (Fowles et al., 1997).

Methods

The present study used a quantitative, descriptive design and targeted African American women who attended four FQHCs in a southern state (Powe, Daniels, & Finnie, 2005; Powe, Daniels, Finnie, & Thomas, 2005). On average, the centers reported seeing 90 patients older than age 18 per five-day week, the majority of which are African American. Annually, the centers provide more than 100,000 outpatient visits to a patient base

Incongruence is the percentage of cases that patients' self-reported screening differed from what was documented in the medical record. Incongruence has two possible scenarios: (a) The patient may report screening has occurred and the medical record does not document it, or (b) the patient may deny screening and the medical record documents that screening has occurred.

Specificity is the percentage of cases that patients reported not being screened and the medical record documents they have not been screened.

Sensitivity is the percentage of cases that patients reported being screened and the medical record documents screening has occurred.

Figure 1. Definitions of Terms

in which more than 80% are at or below the federal poverty level. These centers, located in rural and urban underserved areas, are funded by the U.S. Department of Health and Human Services. Patients served in these centers are considered to be at an increased risk for poor health outcomes as a result of socioeconomic and demographic variables.

Women were eligible to participate in the study if they were older than age 18, oriented to place and person, able to speak and understand English or Spanish, and not in any self-reported or observed distress (physical or emotional). The university's institutional review boards and the medical directors of the centers approved the study.

Instruments

Data were collected using the **Patient Demographic Data Questionnaire (PDQ)** and the **Medical Record Abstraction Form (MRAF)** (Ruffin, Gorenflo, & Woodman, 2000). The PDQ collects basic demographic information, information on medication usage, and family medical history. In addition, questions that assess participation in cancer screening procedures are included. For example, the participants were asked if they have ever had a mammogram and, if so, whether they had the test in the prior year, two to five years ago, or more than five years ago. Trained research assistants were available to define medical terms, such as mammography or Pap test, as needed; most participants were familiar with the terms. The PDQ is written at a sixth-to-seventh grade reading level. Trained research assistants were available to read the questionnaire to the participants if needed. On average, the participants completed the PDQ in 8–10 minutes.

The MRAF was used to abstract information from the medical record that focused on cancer screening and diagnostic testing. The MRAF allows the collection of data about CBE, mammography, Pap tests, and FOBT. Health information, such as year of birth, number of visits in the past year, insurance, and presence of chronic illness, also was collected. The MRAF language and format were targeted toward medical records staff or healthcare professionals. Reliability of the MRAF was not established because it is not a survey administered to participants. The instructions on the MRAF ask the reviewer to check all areas of the chart for the screening information (physician's orders, progress notes, nurse's notes, care plans, radiology reports, laboratory reports, miscellaneous section). Interrater reliability of the MRAF was established by two RNs with 98% agreement.

Procedures

The principal investigator conducted a two-hour training session for all data collectors that included a mock patient interview and an overview of the medical record review. The dates and times for the data collection were prearranged with the medical directors and office managers at each health center. Patients were recruited from the waiting areas of the FQHCs over a consecutive five-day period (9 am–5 pm) by trained data collectors. If a center had evening hours, participants also were recruited during that time period to enhance representation of the patient population. The purpose of the study was explained to participants individually. Informed consent forms and Health Insurance Portability and Accountability Act forms were signed by the participants. Each participant received a \$10 gift certificate to a local grocery store as an incentive for completing the survey.

Following the initial data collection period, dates and times were scheduled with the office manager and the medical records manager to return to the FQHCs to review the medical records. A list of participants was provided to the medical records manager and the records were retrieved by his or her staff. A copy of the informed consent form (giving the researchers permission to review the record) was placed in each medical record as required by the center. Two RNs reviewed the medical record in a secured room using the MRAF. The reviewers discussed discrepancies, difficulties locating information, and difficulties translating information so that the reviews were consistent. The patients' participation in a screening was documented if the results of the screening were listed in the medical record.

Results

The present study focuses on responses from African American women only ($N = 116$). The mean age of the women was 35, with a range of 18–75 years, and their mean education level was 12.6 years, with a range of 8–18 years. Fifty percent of the women were single, 25% were married, 16% were divorced, and 9% described themselves as widows or did not provide a response. Sixty-one percent of the women reported a yearly income of \$10,000 or less. Eighty-eight percent ($n = 102$) of the women were uninsured or insured via Medicare or Medicaid, and 14% smoked an average of eight cigarettes daily. Twenty-five percent reported that their doctors or nurses had discussed cancer with them in the past six months; this rate might be reflective of the fact that the women may not have been to their providers within six months because the study specifically targets screening within the past year.

Clinical Breast Examination

A CBE is recommended every three years for women in their 20s and 30s and annually for women older than age 40. Eighty-six percent of the women who were age 20 or older ($n = 94$) reported having a CBE in their lifetime, 67% in the past year, 20% in the past two to five years, and 10% more than five years ago. Based on medical record documentation, 35% of the women had a CBE in their lifetime, 26% in the past year, 4% in the past two to five years, and 2% more than five years ago.

The results of a Wilcoxon signed ranks test indicated significant differences between the self-report and the medical record documentation for CBE in the past year, in the past two to five years, and more than five years ago ($z = 5.36$; $p < 0.0001$, $z = 3.41$; $p = 0.001$, $z = 2.31$; $p = 0.021$, respectively) (see Table 1). CBE in the past year had a 59% incongruence rate, 28% specificity rate, and 16% sensitivity rate. For the past two to five years, the incongruence rate was 23%, specificity 76%, and sensitivity 1%. More than five years ago had a 12% incongruence rate, an 82% specificity rate, and a sensitivity rate of 0%, indicating that no cases occurred in which the patient and the medical record documented that the CBE had been performed during this time period.

Mammography

Only women older than age 40 ($n = 35$) were included in this analysis because routine mammography is not indicated for younger women at normal risk for breast cancer. Seventy-seven percent of the women reported ever having a mammogram in their lifetime, 29% in the past year, 29% in the past two to five years, and 6% more than five years ago.

Based on documentation in the medical record, 40% of the women had a mammogram in their lifetime, 9% in the past year, 26% in the past two to five years, and 6% more than five years ago.

Significant differences existed between the self-report and the medical record documentation for mammography in the past year ($z = 2.333$, $p = 0.02$) but not for the past two to five years or more than five years ($z = 0.577$, $p = 0.564$, $z = 0.577$; $p = 0.564$, respectively). Mammography in the past year had a 31% incongruence rate, 59% specificity rate, and 10% sensitivity rate. For the past two to five years, the incongruence rate was 40%, specificity 53%, and sensitivity 1%. More than five years ago had a 12% incongruence rate, 91% specificity rate, and 0% sensitivity rate.

Pap Test

Because of an error on the survey, the entire sample did not have the opportunity to respond to the questions about Pap testing. The results represent the subset of women ($n = 43$) who responded to the questions. Ninety-six percent of the women reported ever having a Pap test in their lifetime, 72% in the past year, 26% in the past two to five years, and 12% more than five years ago. Based on documentation in the medical record, 58% of the women had a Pap test in their lifetime, 39% in the past year, 25% in the past two to five years, and 13% more than five years ago.

Significant differences existed between the self-report and the medical record documentation for Pap testing in the past year and more than five years ago ($z = 2.5$, $p = 0.012$), but the past two to five years had no significant differences ($z = 1.5$, $p = 0.132$). Pap tests in the past year had a 45% incongruence rate, 23% specificity rate, and 33% sensitivity rate. For the past two to five years, the incongruence rate was 26%, specificity 67%, and sensitivity 7%. More than five years ago had a 37% incongruence rate, 58% specificity rate, and 5% sensitivity rate.

Fecal Occult Blood Test

Only women older than age 50 ($n = 16$) were included in this analysis because FOBT is not indicated for younger women at normal risk of colorectal cancer. Fifty-six percent of the women reported ever having a FOBT in their lifetime, 35% in the past year, 12% in the past two to five years, and 6% more than five years ago. Based on documentation in the medical record, 11% of the women had a FOBT in their lifetime, 12% in the past year, and 0% in the past two to five years or more than five years ago.

No significant differences existed between the self-report and the medical record documentation for FOBT in the past year, in the past two to five years, or more than five years ago ($z = 1.14$, $p = 0.157$; $z = 1.14$, $p = 0.157$; $z = 1.0$, $p = 0.317$, respectively). FOBT in the past year had a 51% incongruence rate, 50% specificity rate, and 0% sensitivity rate. For the past two to five years, the incongruence rate was 13%, specificity 88%, and sensitivity 0%. More than five years ago had a 6% incongruence rate, 94% specificity rate, and 0% sensitivity rate.

Discussion

Limitations

Generalizing these findings has several limitations. First, because the average age of the women was 35, many of the

Table 1. Incongruence, Specificity, and Sensitivity Across Screening Types

Screening	Time Since Last Screening (Years)	Incongruence (%)			Specificity (%)	Sensitivity (%)
		Total	MR Yes/SR No	MR No/SR Yes		
Clinical breast examination	< 1	59	7	52	28	16
	2–5	23	3	20	76	1
	> 5	12	2	10	82	—
Mammography	< 1	31	3	28	59	10
	2–5	40	17	23	53	1
	> 5	12	3	9	91	—
Pap test	< 1	45	5	40	23	33
	2–5	26	7	19	67	7
	> 5	37	30	7	58	5
Fecal occult blood test	< 1	51	13	38	50	—
	2–5	13	—	13	88	—
	> 5	6	—	6	94	—

MR—medical record; SR—self-report

Note. Because of rounding or missing data, percentages may not total 100.

women were not eligible for mammography or FOBT. As a result, the cell sizes for mammography and FOBT were too small to generalize the findings beyond the current study population. Second, participants were not selected randomly, represented a limited geographic region, and how long they had been attending the FQHC was not clear. Furthermore, the medical record review does not capture conversations about prior cancer screening between the healthcare providers and the patients. Lastly, screenings may have been performed at other centers and not reflected in the current medical record. Rates for CBE may be low because women in their 20s and 30s are recommended to have the screening every three years. However, if the data were misrepresented in this way, a higher rate of CBE in the past two to five years would be expected. The results of the study, however, indicate a higher self-reported rate for CBE in the past year. Nonetheless, the findings raise several key areas for discussion.

This study assessed medical record documentation of screening and self-reported participation in cancer screening for breast, cervical, and colorectal cancer among African American women who attend FQHCs. Because a clear universal standard of an acceptable level of incongruence, specificity, or sensitivity does not exist with regard to screening examinations, determining in a consistent manner the true meaning of the findings, when an intervention needs to occur, and whether the intervention should target providers' or participants' recall or understanding of procedures is difficult. Although not statistically tested, time seemed to influence incongruence and specificity regardless of screening type. For example, the level of incongruence for CBE and FOBT decreased over the given period of recall with much lower incongruence at five years compared to one year. During those same time periods, the level of specificity increased. The higher levels of incongruence for the past year reflect issues of recall for the participant or documentation issues for the medical record. Conversely, the levels of incongruence for the past two to five years and more than five years ago may reflect the fact that the women did not participate in CBE and FOBT, at least not at the current centers.

With the exception of Pap testing (more than five years ago), most incongruence is accounted for by participants

who reported screenings that were not documented in the medical record. On the surface, the findings seem to support the claim that patients often overreport screening (Fiscella et al., 2006). However, an equally plausible explanation is that the participants may not have had the procedures performed at their respective health center given the transient nature of health care in society. Fiscella et al. suggested that racial and ethnic minorities are more likely to be seen by safety net providers; and because of limits in funding, documentation or billing for services may be compromised. Another possible explanation is that the participants may have confused other medical procedures with screening. For example, a woman may have assumed that a practitioner who auscultated lung and heart sounds also was assessing the breast or a woman who had a general vaginal examination may have assumed she had a Pap test. In addition, because procedures such as CBE are not considered a specialized test, they may not have a routine place to document them in the medical record or documentation may have been omitted (Gordon et al., 1993). Although those explanations are not supported by the present study, the broader issue still remains regarding adherence to the recommended screening guidelines and the potential influence that overreporting of screening (if this is the case) can have on public policy. Cancer rates or stage of diagnosis may be regarded as more influential with policy rather than screening; however, the reality is that policies supporting funding for FQHCs potentially can be influenced by whether participants are using the services. For example, if, as Fiscella et al. suggested, racial and ethnic minority patients overestimate their screening, the mortality rate from cancer could increase because of late diagnosis of the disease. Therefore, any policies based on surveys dependent on self-report may result in decreases in funding in the worse case scenario or, at a minimum, no increase in funding.

Implications for Nursing

Most studies that address the relationship between self-reported screenings and medical record documentation among underserved African Americans occurred in the 1990s, with fewer studies addressing the phenomenon since 2000.

Reasons for the lack of ongoing research is unclear given the high percentage of specificity for CBE, mammography, Pap testing, and FOBT found in the present study. Why such a high level of discrepancy exists between self-reports and the medical records is unclear. Nurses are in a unique position to capture this type of information and better evaluate the reasons for the high levels of incongruence among African American women. Some women may assume that a mammogram is inclusive of a CBE or that a general pelvic examination is the same as a Pap test. Nurses may need to have a follow-up discussion with the women to assess their understanding of the tests and procedures that were completed. Nurses also are uniquely positioned to educate women about the types of age-specific cancer screening and risk reduction. The provision of this information should not be limited to oncology-related visits because several cancer risk factors (diet, inactivity, and smoking) are risk factors for cardiovascular disease and diabetes.

The issue of inaccurate recall of the time frame for screening also should be explored because women may not have had the procedures as recently as they report. Clearly, nurses may not be able to directly influence patients' information recall, but they might play a role in designing patient reminder systems about screening or providing a written summary of tests and procedures patients have during an office visit.

Nurses also can initiate multidisciplinary research that addresses the high rate of specificity documented in the current study, which is important and should target patients and their providers. Nurses often are the first professional provider patients encounter in the healthcare system. Research is needed to validate the use of cancer screening reminder systems for patients and prompts for providers to remind them to offer screening. Other research should explore patient and provider perceptions regarding responsibility and accountability for screening. For example, some providers may believe patients should be accountable for recalling whether they have been screened, whereas patients may believe it is the provider's responsibility. This type of incongruence can have implications for whether the subject of cancer screening is discussed during an office visit. Although extremely basic, the need for consistent documentation in the medical record cannot be overemphasized. In most cases the medical record is viewed as the acceptable legal standard, but research is needed to establish an acceptable standard for incongruence, specificity, and sensitivity for cancer screening. These standards would provide researchers and healthcare providers a marker to assess the outcomes of screening efforts and provide insight into the types of interventions needed to address high levels of incongruence or specificity.

Educational interventions may be needed for patients and providers. Tailored programs might enhance patients' and

providers' knowledge of cancer screening and early detection guidelines and available programs (Powe, Daniels, Finnie, & Thomas, 2005). Basic information about cancer received in nursing school may not be sufficient to fully capture the range of cancer screening and early detection needs of patients. Additional training and ongoing inservice education for nurses and other providers could be beneficial. When patients receive factual information about cancer, it will then be feasible to speculate that they are in a better position to pass this information on to their family and friends. Furthermore, a provider's recommendation for screening continues to be a primary factor that influences patients' decisions to screen. Thus, making sure that providers have factual information about cancer screening and early detection programs is important (Lisovicz et al., 2006).

Culturally and educationally appropriate materials that use a variety of media formats should be available in healthcare center waiting areas. The information can be tailored to meet the needs of the groups most served by each individual center. Additional efforts could focus on ensuring documentation of screening in the medical record and conversations between providers and patients about screening. This strategy could help to evaluate the sources of incongruence between the self-report and the medical record. Finally, findings from this study may have implications for nurses' roles in public policy. National databases that rely on self-reported screening behaviors could present a clearer picture of screening practices if the level of incongruence was diminished, resulting in more efficient allocation of funds, decreases in redundancy of services, and more effective creation of services and collaborations. Although seemingly a monumental task, efforts to compare self-reported screening from databases with a medical record review would provide further information on these issues.

Conclusion

Nurses remain at the forefront of patient education and care. Patients should be able to adequately relay information about previous cancer screening procedures and that information should be documented clearly in the medical record. However, with the transient nature of health care in an imperfect world, that is not always the case. Research to identify the best strategies for achieving congruence between self-reported screening and the medical record documentation is needed to ensure that African American women, who suffer a disproportionately high cancer burden, are receiving cancer screening tests.

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