



Pap Test Follow-up Pattern Among American Indian Women in Arizona

## Journal of Health Disparities Research and Practice

Volume 4 | Issue 1

Article 4

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2010

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#### Recommended Citation

Eisenberg, Merrill; Coe, Kathryn; Wilson, Charlton; Evans, Kathleen; and Brewer, Elizabeth (2010) "Pap Test Follow-up Pattern Among American Indian Women in Arizona," *Journal of Health Disparities Research and Practice*: Vol. 4 : Iss. 1 , Article 4.

Available at: <https://digitalscholarship.unlv.edu/jhdrp/vol4/iss1/4>

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## Pap Test Follow-up Pattern Among American Indian Women in Arizona

### Abstract

**Objective:** To quantify the loss to follow-up rate after abnormal Pap test results at the Phoenix Indian Medical Center, an Indian Health Service regional facility, and identify barriers to follow-up from the patients' point of view.

**Materials and Methods:** Patient records were used to identify women who had abnormal Pap tests in 2002 and to document the status of their follow-up care. Women who had no clinical record of follow-up were contacted by telephone to arrange a follow-up appointment and to request participation in a structured qualitative interview to identify barriers to follow-up at the individual, family, community, and health care system levels. Structured qualitative interviews were conducted with 15 women.

**Results:** Of the 930 women with abnormal Pap test results in 2002, 11.1% received follow-up care at PIMC in accordance with the recommended time frame stipulated in clinical protocols; 74.6% received follow-up care at PIMC, but not in accordance with protocols; 2.6% were followed-up at another facility, 1% had moved out of the area, 3.5% were never treated, and we were unable to contact 6.6%. Most of the barriers to follow-up were related to communicating the need for follow-up and providing access to care within a time frame appropriate for clinical care.

**Conclusion:** While these findings place an important additional responsibility and burden on the health care system serving American Indian women, our research outreach efforts suggest that given the availability of appropriate resources, these barriers can be overcome.

### Keywords

American Indians; Delivery of Health Care; North America; Pap Test

### Cover Page Footnote

The project described was supported by Grant Numbers U01 CA086122 and U01 CA114696 from the National Institutes of Health/National Cancer Center. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH/NCI.

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## **Pap Test Follow-up Pattern Among American Indian Women in Arizona**

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### **ABSTRACT**

**Objective:** To quantify the loss to follow-up rate after abnormal Pap test results at the Phoenix Indian Medical Center, an Indian Health Service regional facility, and identify barriers to follow-up from the patients' point of view.

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**Key Words:** American Indians, North America, Pap Test, Delivery of Health Care

## INTRODUCTION

Cervical cancer among American Indian/Alaska Native (AIAN) women is a health problem that is of growing concern. Although calculated rates may vary depending on how AIAN race is determined (Swan et al., 2006) several regional analyses over the past twenty years have demonstrated a cervical cancer incidence disparity for AIAN women (Horm and Burhansstipanov, 1992; Baquet, 1996; Bleed et al., 1992; Leman et al., 2005), and higher rates of abnormal Pap smear findings (Bernard et al., 2001), although there are exceptions (Paltoo and Chu, 2004). A recent comparison of AIAN cervical cancer rates with those of non-Hispanic white women residing in Indian Health Service Contract Health Service Delivery Areas (where calculation of race is likely to be most accurate), found that AIAN women had significantly higher cervical cancer rates overall (Becker et al., 2008), with variation by region. Other national data (Singh et al., 2004) suggest that the cervical cancer rate among AIAN women is impacted by poverty to a higher degree than it is among other racial/ethnic groups. Between 1975 and 2000, the incidence of cervical cancer among AIAN women was 292% higher in low socioeconomic census tracts compared to AIAN women residing in high socioeconomic census tracts. While the relationship between socio-economic status (SES) and cervical cancer incidence was also demonstrated in other populations (ranging from 30% for blacks, to 97% for non-Hispanic whites), the magnitude of difference was considerably higher for AIAN women than for women in any other ethnic group.

Once diagnosed with cervical cancer, AIAN women are more likely to die than women from other racial/ethnic groups (Espy et al., 2005; Cobb and Paisano, 1998; Samet, 1987; Horn and Burhansstipanov, 1992; Leman et al., 2005, pp.10-12). As with incidence, cervical cancer mortality is more impacted by SES among AIAN women than among women in other racial/ethnic categories. The mortality rate for AIAN women residing in low SES counties was 200% higher compared to AIAN women residing in high SES counties. The differential for other racial/ethnic groups ranged from 46% for non-Hispanic white women and 82% for Hispanic women (Singh, 2000).

Identifying and treating cervical cancer early in the disease process improves patient outcomes (USPSTF, 1999). One likely reason cervical cancer mortality rates are relatively high among AIAN women may be that as a group they have low rates of Pap test screening (Mahmoodian, 1987; Young, 2000; Bernard, 2001, pp.14-16) resulting in diagnosis at a later stage of the disease. An exception is that Satter et al. (2005) found that 97% of adult AIAN women in California participating in the California Health Interview Survey in 2001 reported ever having a Pap test and 90% reported having had a test in the past three years. However, these high screening compliance figures may be an artifact of using a telephone survey methodology, which excludes women who have no telephone.

Another reason for increased cervical cancer mortality is that even when AIAN women participate in cervical cancer screening, many do not receive the necessary follow-up care. A 1992 study of Pap test follow-up among AIAN women seen in twelve IHS and tribally operated clinics in Washington, Oregon, and Idaho found that 25% of recommended colposcopies following abnormal Pap test results were not completed (Yarboff et al., 2003). Other research (Gilbert et al., 1995; Fox et al., 1997) shows that follow-up rates are even worse for some other high-risk populations. In a logistic regression analysis comparing follow-up rates for racial and ethnic groups in California's Breast and Cervical Cancer Control Program (Fox et al., 1997), loss-to-follow-up rates for women with Pap findings of ASCUS, Low Grade SIL, High Grade SIL and Squamous Cell Carcinoma were lowest for white women (52.9%) followed by AIAN women (63.9%), with all other groups having higher rates. However, when examining the subset of women with High Grade SIL and Squamous Cell Carcinoma, AIAN women fared the worst, with 33.3% not followed.

Factors that have been related to low cervical cancer screening and follow-up in AIAN women include limited access to health care and use of traditional healers (Hodge et al., 1996), low

perception of risk (Risendal et al., 1999), and the “newness” of cancer as an issue among AIAN women (Hodge et al., 1996). Cultural beliefs that may contribute to low cancer screening rates in AIAN populations include beliefs related to modern medical procedures for detecting and treating cancer, a tendency to not seek medical care unless ill, present time orientation, explanatory models of cancer, belief that speaking about cancer will cause it, and modesty (Solomon and Gotlieb, 1999). Modesty, taboos, use of alternative traditional healing practices, illness beliefs, education, concepts of disease, and communication styles may also play a role (Hodge et al., 1996; Solomon and Gotlieb, 1999).

We examined Pap test follow-up at the Phoenix Indian Medical Center (PIMC). PIMC is an Indian Health Service regional facility that provides a comprehensive range of primary and specialty medical services as well as community health services and education. PIMC serves 49,000 patients on six reservation-based AIAN communities and in the off-reservation population of AIAN who reside in metropolitan Phoenix/Maricopa County, Arizona. Indian Health Service eligible women may receive routine Pap tests in any of PIMC’s primary care or women’s clinics. Patients must place a call to the appointment desk to schedule an examination. The average time from a call to an appointment is approximately eight to twelve weeks. When an abnormal Pap result is found, the patient is sent a form letter identifying the abnormality and advising the patient to call to schedule a follow-up appointment. A copy of the letter is kept in the patient’s file. If the patient does not make a follow-up appointment, the medical provider reviewing the patient’s file initiates second and third letters at approximately three-month intervals for a total of three letters over a period of six months. If a patient with a severely abnormal Pap fails to have follow-up, other efforts, including Public Health Nurse referral, may be utilized to contact the patient and encourage her to come in.

Despite these efforts, many women fail to return for follow-up according to the standard guidelines. This research was undertaken to track all women who were seen at the PIMC Women’s Clinic and Primary Care Clinic who received abnormal Pap test results in 2002 in order to determine the disposition of their follow-up care and to identify barriers to abnormal Pap test follow-up at PIMC from the women’s point of view.

## **METHODS**

The Resource and Patient Management System (RPMS), an integrated suite of clinical, administrative, and financial software that is utilized by the Indian Health Service, was queried to identify all Pap tests performed on the PIMC campus in 2002 that had abnormal results. Pap tests were determined to be abnormal in accordance with consensus guidelines for the management of histology and cytology established by the American Society for Colposcopy and Cervical Pathology and that were in effect at the time of the research (Wright et al., 2002; Wright et al., 2003). A query of the RPMS system identified 930 patients who had abnormal Pap test results in 2002. The process used to follow the disposition of all abnormal Pap tests was as follows: a spreadsheet file was created by downloading information from the RPMS system, including the initial abnormal Pap results and dates, and all subsequent related clinical encounters and dates for each patient. A related clinical encounter was defined as a repeat Pap smear, colposcopy with or without biopsy, or surgical procedure including loop electrocautery excisional procedures (LEEP), cryosurgery, and/or cold knife cone biopsies. Subsequent related clinical encounters during 2002 through October 2003 were captured. This timeframe allowed for at least nine months to have elapsed after the initial abnormal finding, enough time for women to have received all three call back letters and schedule an appointment.

Using the American Society for Colposcopy and Cervical Pathology’s 2001 guidelines for the management of women with cervical cytological abnormalities (Wright et al., 2002) records were coded as having had full follow-up (subsequent clinical encounter within two months of the index

encounter), partial follow-up (subsequent clinical encounter, more than two months after the index event), and lost-to-follow-up (no subsequent clinical encounter). There were 217 patients identified as not having had a subsequent clinical encounter as of October 31, 2003, which was at least nine months after the index events. We requested the clinical records of these 217 patients in November, 2003; thirteen charts were not available at that time. A total of 204 charts were reviewed by a nurse-midwife working in the PIMC women's clinic, with consultation with the clinic's physicians. Upon examination it was found that follow-up had been documented in an additional 28 charts, leaving 176 charts that documented loss-to-follow-up.

One year later we performed an administrative review of 189 charts (176 with no record of follow-up and 13 charts that had been missing at the clinical review) to verify eligibility for care at PIMC and to gather contact information for a follow-up telephone call. All charts were available at this time. During this process, six women (3.2%) were found to not be eligible for follow-up at PIMC because upon they were non-Indians who had been eligible for their Pap smear at PIMC because they had been pregnant with an Indian child. After the pregnancy, they were no longer eligible for services. This left 183 women in the pool of patients lost-to-follow-up.

We attempted to contact all 183 women who had been identified as being lost-to-follow-up to determine if they had ever been treated. PIMC staff retrieved contact information from these patients' paper files and made aggressive efforts to locate them, making up to seven telephone calls to locate each individual, sometimes calling next-of-kin to find forwarding information. Of the 183 women, 122 (66.6%) were located. Through these telephone calls we identified women who had moved out of the area, who had received treatment elsewhere, who had received treatment at PIMC after our clinical chart review in November 2003, and who had never received treatment. Women who had never been treated and were still in the area were encouraged to make an appointment for follow-up and were invited to participate in an individual interview to discuss barriers to Pap smear follow-up. The names and contact information of those who agreed to participate were forwarded to the research team. A trained AIAN woman called each prospective participant and arranged a time and place to conduct the interview at the patient's convenience.

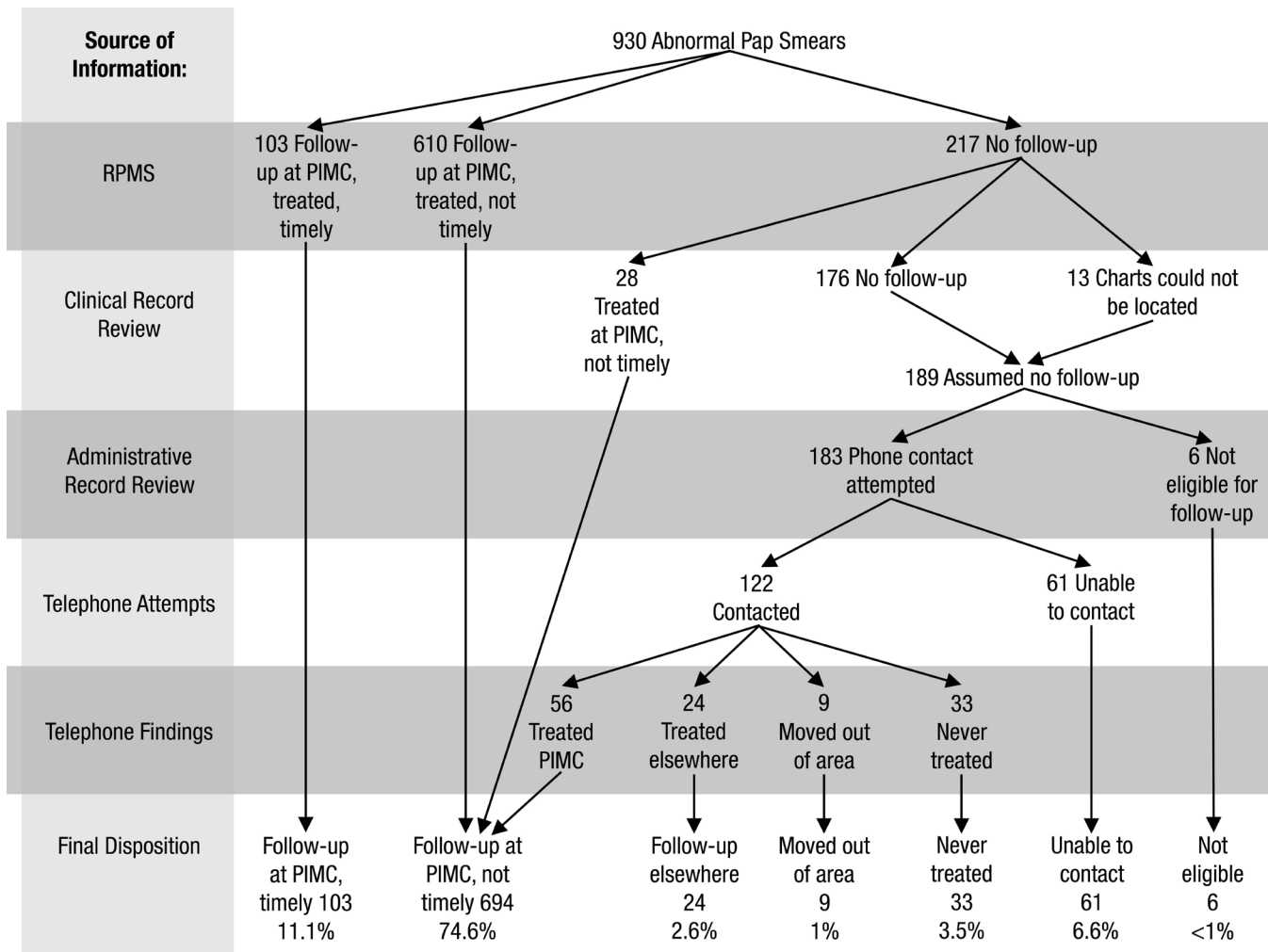
The interview format was structured, included many open-ended questions, and was implemented in a conversational style. The interview addressed potential barriers to follow-up in the individual (fear, co-morbidity, demographic characteristics, knowledge and attitudes about Pap smears and cervical cancer), the family/social network (composition and structure, resources, sources of advice), community (transportation availability, distance), and in the PIMC system (gender of the provider, appointment making, clinic experiences). In addition, we administered a traditional behavior scale that included items regarding language, participation in traditions, and social network. Demographic information, including age, education level, employment status, AIAN blood quantum, and prior pregnancy was documented for each participant. Women who participated in the interview were offered a \$50 gift card.

All research protocols and materials were reviewed and approved by the University of Arizona Human Subjects Protection Program, and the Phoenix Area Indian Health Service Institutional Review Board.

## RESULTS

Figure 1 shows the disposition of all 930 abnormal Pap smears from 2002. Relying solely on the RPMS data, the loss-to-follow-up rate was 20.3%. After completing the clinical record review, the administrative record review, and the telephone call, we found that only 11.1% had been treated at PIMC within the timeframe specified by ideal clinical protocols; an additional 74.6% had been treated at PIMC, but not in a timely manner, 2.6% had been treated elsewhere, and .6% were not eligible for follow-up at PIMC. Those considered lost-to-follow-up included 3.5% who confirmed they had

**Figure 1. Disposition of Abnormal Pap Smears in 2002.**



not received follow-up care, 1% who had moved out of the area, and 6.6% who we were unable to contact. This resulted in an overall loss-to-follow-up rate of 11.1%.

Although PIMC has a protocol for notifying patients who have abnormal Pap smear results that includes use of mailed notices, full follow-up procedures were documented in the records of only 12 (6.8%) women who had no record of follow-up in their clinical record. Partial follow-up (one or two letters) was documented for 139 women (79.0%); 25 (14.2%) women who had no record of follow-up had no documentation of any follow-up letters in their files.

Of the 33 women we were able to contact who had never received follow-up care, 15 (45%) agreed to be interviewed. The women interviewed ranged in age from 25-61, with an average age of 38.8. Ten of the fifteen reported that their AIAN blood quantum was 100%; the other five ranged from 13-75% AIAN blood quantum. Two had less than a high school education, three had a high school education, nine had some college, and one had a two-year college degree. All reported that they work outside of the home from 15-42 hours per week, with an average of 35.3 hours per week. All but one of the women had been pregnant at least once. Traditionality scores ranged from one to five, with one meaning most traditional and five meaning least traditional. One third of the women scored as most traditional (scores ranging from 1.6-2.6), one third scored in the moderate range (2.8-3.5), and one third scored as least traditional (3.8-4.2). This suggests that the women we interviewed represented a range of adherence to traditional practices.

Table 1 summarizes the reasons for lack of follow-up mentioned by the women we interviewed, by level of traditionality. They are organized by the locus at which they occur – in the system, at the individual level, at the family level, or in the community. Most reasons for lack of follow-up resided in the system. Seven of the fifteen women we interviewed stated that they had not followed-up because they had not been notified of the need to do so. One woman commented “I was never called or sent a notice that my test was abnormal so I figured everything was normal.” Another said “No, I never received a notice or phone call that my test was abnormal. I did try to get an appointment this past June and I was told to call at a later date.”

**Table 1. Reasons for Lack of Follow-up, by Level of Traditionality: Number of Mentions**

Locus of Reason	Reason for Lack of Follow-up	Level of Traditionality				Total mentions by Locus
		High	Moderate	Low	Total	
System	Was never told follow-up was needed	3	2	2	7	19
	Problems making the appointment	1	3		4	
	Don't like the long wait in the waiting room		1	1	2	
	Upset /distrustful of PIMC /staff	1	2	1	4	
	Provider gender		2		2	
Individual	Low understanding	1			1	5
	Fear of test		1	1	2	
	Fear of findings		1		1	
	Forgot		1		1	
Family	Other priorities (busy, things come up, husband's illness)	1		1	2	2
Community	Transportation problems			2	2	2

Our clinical record review showed that after being notified of the need to return at least once, 72 women (7.8%) had made at least one appointment for follow-up, but never kept the appointment(s). The interviews revealed a range of issues that are related to not keeping appointments that were made. These include difficulties remembering the appointment, transportation problems, and situations that arise that make it difficult to keep the appointment, such as work issues, other illnesses in the family, or other situations that have a higher priority. The long wait in the waiting room is also a factor women consider when deciding if they are able to keep their appointment. As one woman said, “I get upset, angry and frustrated, especially when my kids are with me, because I don't know what is taking so long. It would help if the nurse or someone came out to let me know how much longer it will be or the reason why it's taking so long...” Another remarked “Yes it [the wait] did create problems, because when my son has to be dropped off at school or other things I have to do, sometimes I have to catch a ride and I can't give a definite time when I will be seen.”

Perhaps the most daunting barrier to receiving follow-up care identified by the women we interviewed was simply the process of calling to make the appointment. A range of frustrations regarding the appointment scheduling process was described:

*...it's hard to get in...[I was] on hold for thirty minutes and then was told to try again as they were booked up.*

*It's frustrating for me when I try to call for an appointment. All I ever get is we're not taking any*



*appointments until the beginning of the month or to call after 8:00 a.m., then I end up getting busy and I forget about the appointment.*

*I called several times and was told there were no appointments available, that the schedule was full. They told me they would send a notice when there was an opening and I never received one.... When I checked - I was told to call again - but was told the same thing - no open spots in the clinic and I never received a phone call or a letter regarding any openings in the schedule... Sometimes I have to wait for the call to go through and sometimes it just rings and rings.*

The interviews also reveal knowledge and attitude issues that discourage women from making and keeping their follow-up appointments. For example, the unavailability of appointments can send the message that it is not important to follow-up. As one woman said, "I wish they would make it easier instead of making it confusing to get an appointment. I can't get an appointment right away; if they don't think it's serious then I just let it go."

Several women reported that they avoid coming back because they dislike the exam:

*Just hearing that my mom and her mom never had to go through those tests, I think it's embarrassing to get them done.*

*I did get a letter regarding the test results, but I didn't want to go back because of the thought of having pain.*

Finally, several women made comments suggesting that they do not understand the importance of follow-up after having an abnormal Pap test or avoid the test because they do not want to have bad news:

*I'm also afraid of what they might find when they do tests and I don't want to find out if something is wrong.*

*My mom had something similar and she said she was fine after a while, without having to go back, so I didn't.*

*I didn't go because my test always comes out abnormal. I figure it's because of my diabetes and yeast infections. I did get a letter about the abnormal test but I didn't go back because they are always abnormal.*

Reasons for lack of follow-up do not appear to be related to level of traditionality. When asked "Does having a Pap test violate your cultural traditions?" all but two women answered "no." One woman, who scored as highly traditional said "[y]es and no. The Medicine Man doesn't do them, but I know it's for my own health and to go along with the modern ways." Another woman, who scored as moderately traditional said "[k]ind of, because it's disgusting."

### **Limitations of the Research**

Given the small number of women involved in this research, and the uniqueness of the health care facility in which the research took place, we cannot generalize the results to a larger population.

## **DISCUSSION**

Even with efforts to prevent the spread of Human Papilloma Virus through education and safe sexual practices and introduction of immunization programs, use of appropriate screening and treatment interventions for cervical cancer and its precursor lesions will continue to be the key method for reducing the burden of cervical cancer mortality in this population for many decades to come. The success of this strategy will be very dependent on the ability to follow through with the screening and treatment process.

Our research demonstrated that using the electronic information system to determine the loss-to-follow-up rate resulted in an overestimate of the number of women who did not receive follow-up care. The proportion of women lost-to-follow-up was decreased from 23.3% to 11.1% after examining medical charts and contacting women by telephone. This compares favorably with the results of studies of loss-to-follow-up after abnormal Pap results in other populations (Satter et al., 2005). Unfortunately, the source of information about loss-to-follow-up in many other studies is not clearly delineated. It is problematic to compare our findings, which are based on several levels of record review and aggressive efforts to locate women with no record of follow-up to determine if they had received care elsewhere, to findings from other studies. Further, while the loss-to-follow-up rate in our population was relatively low, it is important to note that only 11.1% of women received follow-up care in accordance with recommended clinical guidelines.

Importantly, we found that most of the barriers to follow-up appear to reside within challenges of the health care system in communicating the need for follow-up and in providing access to care within a timeframe appropriate for clinical care. These findings are consistent with an analysis by the Cervical Cancer Mortality Project (CCMP) of the National Cancer Institute's Center to Reduce Cancer Health Disparities (Freeman and Wingrove, 2005). In this expert panel analysis of many data sources related to the problem of mortality from cervical cancer, the CCMP participants identified major areas of emphasis in which policy changes and interventions at Federal, State, and local levels could significantly impact women's health and reduce cervical cancer mortality. Outreach, navigation, information and communication were among the factors identified. Our analysis extends the CCMP findings to AIAN women.

Looking at patient-level barriers to follow-up care, we found that cultural identity or traditional mores did not appear to be barriers to follow-up. Women with all levels of traditionality reported the same array of barriers. As has been described in other studies (Solomon and Gotlieb, 1999; Coe et al., 2004), traditional women recognize the need for screening and follow-up for cervical cancer. Barriers reported also did not vary by other individual level variables, including age, education level, or employment status. At the individual level, we did find evidence that some of our interviewees found provider gender, dislike of the examination procedure, transportation limitations, and challenges with familial and work obligations as barriers to follow-up, and these issues must be addressed. However, these issues were less common than the previously mentioned access and communication factors.

The good news is that our research suggests that the underlying reasons for lack of follow-up after an abnormal Pap test are potentially solvable. Contrary to conventional wisdom, use of the telephone to track women in need of follow-up is feasible in this population. We were able to contact approximately two thirds of the women initially classified as lost-to-follow-up almost three years after the initial abnormal finding. This suggests that with the increased intensity and resources that were available because of this investigation, women can be engaged in the follow-up process.

Our research does have some limitations. We used retrospective electronic records to identify women who were lost-to-follow-up. Because of the retrospective nature of our research, we do not have the details of the efforts, barriers, perceptions, or solutions that did occur in arranging follow-up, even if delayed, for the vast majority of women during the research period. Knowing these issues and solutions as they occurred would add important knowledge to our investigation. Also, our sample of women informing our qualitative analysis was small, which limited our ability to identify important issues within subsets of women with similar issues. For example, our traditionality scale was designed to identify more and less traditional women, using certain criteria which may be problematic (Coe et al., 2004) and the sample size in the low, moderate, and high traditional groups was low and may not be representative. Also, those who declined to be interviewed may have reported different barriers.

However, the systemic barriers consistently reported here, by women of all levels of traditionality, suggest that these issues are likely to be common to many AIAN women.

In summary, we found that the key barriers faced by AIAN women to following-up with abnormal Pap smears appear to reside within challenges of the health care system in communicating the need for follow-up and in providing access to care within a timeframe appropriate for quality clinical care. Women at risk, health care advocates, and Federal, State, and Tribal partners should view this as an opportunity to create the systems and processes necessary to find solutions to these barriers. Combined with new and important opportunities for prevention such as HPV vaccine, such solutions should lead to the promise of reducing this unnecessary health disparity.

## ACKNOWLEDGMENT

The project described was supported by Grant Numbers U01 CA086122 and U01 CA114696 from the National Institutes of Health/National Cancer Center. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH/NCI.

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