

Low-Income Minority Women at Risk for Cervical Cancer: A Process to Improve Adherence to Follow-Up Recommendations

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SYNOPSIS

Objective. The Houston Department of Health and Human Services (HDHHS) has a centralized process for notifying and setting up follow-up appointments for women with abnormal Pap smears who are clients of HDHHS health centers. Faculty and a student from the University of Texas School of Public Health and HDHHS personnel jointly conducted a study to evaluate the process and performance of the system.

Methods. The study examined two subpopulations: women with atypical squamous cells of undetermined significance or low-grade squamous intraepithelial lesions (ASCUS/LGSIL) and women with high-grade squamous intraepithelial lesions or atypical glandular cells of undetermined significance (HGSIL/AGCUS). A retrospective study was conducted of data on women attending eight HDHHS clinics during the period from February 1996 through August 2000. Records of 1,216 women referred for evaluation of abnormal Pap smears were reviewed. Process effectiveness was measured by the number of successful contacts made and the number of appointments set up. Performance was measured by compliance with referral appointments. Predictors included race/ethnicity, age, co-existence of a sexually transmitted disease, number of prior referrals, type of patient visit, and health center attended.

Results. HDHHS staff successfully notified 95.6% of women with ASCUS/LGSIL and 97.9% of women with HGSIL/AGCUS. Using performance criteria as outcome measures, high-risk women requiring targeted interventions were identified. Overall, 84.2% of women scheduled appointments. Among those with ASCUS/LGSIL, women identified as African American were 53% less likely to accept an appointment and 45% less likely to show up for the appointment than those identified as Hispanic or "other." Age and type of patient visit appeared to be significantly associated with patient compliance behavior.

Conclusion. The study describes the effectiveness of a centralized patient follow-up process for women at risk for cervical cancer.

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Pap smear screening in the United States is recognized as a successful prevention program, but it has been described as both a triumph and a tragedy.¹ The triumph is reflected in the significant reduction in cervical cancer deaths in the U.S. over a 30-year period. The rate of reported deaths has decreased from 9.3 per 100,000 in 1950–1954 to 2.6 per 100,000 in 1983–1987.² The tragedy is that the cervical cancer mortality rate in the U.S. has essentially remained unchanged for the last decade and a half. The plateauing of this rate has caused increasing public health concern, as the survival rate for women with precancerous abnormalities (CIN lesions) approaches 100% with appropriate evaluation, treatment, and follow-up.³

This flattening of cervical cancer mortality rates may be associated with differing perceptions of risk, competing cultural values, and racial/ethnic disparities in health status, access to health care, and utilization of health care services. While the Healthy People 2000 target objective for total cancer deaths was reached, the proportion of women who died from cervical cancer increased in 1995 to 5.2 per 100,000 for African American women and 3.1 per 100,000 for Hispanic women.⁴

In 1989, Koss suggested four policy objectives to further reduce morbidity and mortality from cervical cancer: (a) target high-risk women for Pap smear screening, (b) establish measures to ensure adequate quality control in obtaining and interpreting the smears, (c) develop interventions to maximize the return rates of women with abnormal test results, and (d) initiate measures to ensure appropriate care for women needing follow-up treatment.¹ These suggestions were reflected in the Healthy People 2000 target objectives for cervical cancer screening.⁵

At the national level, Koss's first suggestion was addressed through enactment of the Breast and Cervical Cancer Mortality Prevention Act in 1990. That act authorized the Centers for Disease Control and Prevention (CDC) to establish a national program to increase breast and cervical cancer screening among uninsured and low-income women. In 1991, the CDC launched the National Breast and Cervical Cancer Early Detection Program. Through cooperative agreements with states, tribes, and tribal organizations, this program provides funds to state and local public health departments and other agencies that can demonstrate their ability to offer comprehensive breast and cervical cancer screening programs that include follow-up and case management components.³

The second objective proposed by Koss—ensuring adequate quality control in obtaining and interpreting Pap smears—has been addressed through revisions

of the Clinical Laboratory Improvement Act. These revisions have mandated licensure of laboratories, cytology workload limitations, quality assurance measures for rescreening of normal Pap smears, and a review process for abnormal smears that includes tracking of follow-up testing. The Act set the framework for the Bethesda System, which has since established a standard terminology used in the analysis and interpretation of Pap smears. In addition, test findings are required to include an evaluation of specimen adequacy and pathology recommendations for follow-up care.

Attempts to achieve the last two of Koss's objectives—maximizing the return rates of women with abnormal test results and ensuring appropriate care for women needing follow-up treatment—have been less successful. Clinically, ensuring appropriate care for women needing follow-up treatment is complicated by the etiology of cervical cancer, rates of regression and progression, and the lack of medical consensus on treatment options. From a public health perspective, barriers appear to be grounded in racial/ethnic disparities in cervical cancer screening and management (follow-up and treatment services).⁶

Adherence to follow-up recommendations

While researchers continue to investigate factors associated with patient adherence to follow-up recommendations, the lack of a baseline measurement makes comparisons difficult. Reported adherence rates range from 20% to 74%,⁷ depending on practice setting (private, nonprofit, or public),^{2,8–10} type of recommendation (repeat Pap smear vs. colposcopy),^{8,11–14} socioeconomic factors,^{11,15–17} and patient beliefs and attitudes.^{19–21}

The effects of practice setting may reflect patients' ability to pay for services. Paskett and colleagues are the only investigators who have studied adherence in a mixed practice setting that included women from all socioeconomic groups.¹⁰ In their study, only 51% of participants complied with the recommendation for a repeat Pap smear. In a retrospective cohort study of three nonprofit family planning clinics in Northern California, Melnikow et al. found a 52.9% adherence rate for a repeat Pap smear visit and a 61.1% rate for colposcopy.⁸ In contrast, Marcus et al. found a range of adherence rates of 58% to 87% among women attending 12 county clinics.² Investigating repeat smear follow-up rates in a college health population, Friesch found a 69% return rate.⁹

Studies investigating patient adherence and follow-up recommendation (repeat Pap smear or colposcopy) reflect the severity of disease and women's perception

of risk. In general, follow-up rates for colposcopy are lower than those for repeat Pap smears, with adherence rates of 60% to 70%.⁷ In an 18-month study at a community-based clinic in Chicago, Lacey et al. found a 69% rate of adherence to follow-up recommendations among women with “suspected malignancies” and a 45% rate among women with “more limited gynecological conditions.”¹² Laedtke and Dignan found that most women referred to a dysplasia clinic for colposcopy failed to keep their first appointment and that 32% did not complete treatment.¹³ In contrast, McKee et al. conducted a telephone survey of women attending an inner-city family health center in New York City, reporting a 75% adherence rate among the 79% of women successfully contacted.¹⁴

Socioeconomic characteristics of women with abnormal Pap findings have been investigated in terms of risk for poor follow-up. In a retrospective descriptive study of women attending a family practice residency clinic, Carey and Gjerdingen reported an 85.3% adherence rate for diagnostic follow-up (repeat Pap and/or colposcopy) and a 79.5% adherence rate for treatment.¹⁵ The demographic descriptors for these groups included age (mean age of 29.7 years), government subsidy (63.2% were on medical assistance), and race/ethnicity (51.6% were identified as white, 24.2% as African American, 18.9% as Southeast Asian, and 5.3% as “other”). Kaplan et al. assessed background characteristics and return rates for follow-up by examining records of low-income women with cervical abnormalities at primary and secondary clinics operated by a local health department in Los Angeles County.¹⁶ The study found that 28.5% of these women received no follow-up care and that women who received no follow-up care were more likely to be “non-Latino” than “Latino” and more likely to be unmarried than married. Only 58% of the women studied completed all recommended treatment. Those who received some care were more likely to be <20 years of age and pregnant and single. In contrast, Cartwright and Reed found no correlation between race/ethnicity or severity of disease and “no show” behavior, but did find “no show” behavior to be correlated with age (<30 years old) and pregnancy.¹¹ In a randomized intervention study with women who were mostly (90%) Hispanic, were married or living with a significant other, were relatively young (83% were <44 years old), and the majority of whom (65%) had no source payment for health care, Marcus et al. found that 36.1% of the control group were lost to follow-up.¹⁷

Specific compliance behavior to follow-up recommendations was documented only in the study by Cartwright and Reed,¹¹ who studied patients of a county

hospital referral colposcopy clinic by monitoring daily appointment logs and tracking patient adherence over a 24-month period. They found that 21% of the women made only one appointment and failed to keep it (complete loss to follow-up), 40% failed to keep their first appointment, and 68% failed to keep at least one appointment. On any single clinic day, an average of 39% of appointments were “no shows.”

Causes of nonadherence to follow-up recommendations are only partially understood.⁷ Investigators have suggested that barriers, which may or may not be interrelated, may include limited understanding of Pap smear results; fears associated with abnormal findings; lack of health insurance, of child care accommodations, or of transportation; administrative provider problems; and poor communication or rapport with the provider.^{18–21} Lawson et al. have suggested that access to care and cultural behavior may also be related.⁶ All of these studies were relatively small, involving the use of focus groups and self-administered questionnaires.

Interpretation and comparison of findings across these studies is hindered by unreported referral protocols and the lack of a definition for follow-up (kept appointments vs. partial, complete, or no follow-up).¹⁶ Few studies have evaluated patient adherence to recommendations for repeat Pap smear screening and colposcopy separately, and few have investigated whether there is an association between severity of disease reported, patient history of a previous abnormality or sexually transmitted disease (STD), or prior referral history.

This study attempted to bridge some of these gaps by investigating the process and performance effectiveness of a centralized Pap smear follow-up protocol established by the Houston Department of Health and Human Services (HDHHS) and by identifying potential variables associated with becoming “lost to follow-up.” Staff from HDHHS and faculty and a student from the University of Texas School of Public Health (UTSPH) jointly conducted the study. UTSPH personnel were responsible for the research design, data abstraction, and statistical analysis. HDHHS staff provided clinical expertise and data.

METHODS

Research design

We constructed an algorithm of the referral and follow-up process for women with abnormal cytology results, creating two principal subpopulations:

1. Women with atypical squamous cells of undetermined significance (ASCUS) or low-grade

squamous intraepithelial lesions (LGSIL) are considered at less risk than women with other kinds of lesions. However, if these conditions are found on consecutive Pap smears, the risk of progression increases. Suggested follow-up is three to four months after the second consecutive abnormal finding.

2. Women with high-grade squamous intraepithelial lesions (HGSILs) or atypical glandular cells of undetermined significance (AGCUS) are considered to have a higher risk of progression to cervical cancer than women with ASCUS/LGSIL. Suggested follow-up is one month.

We conducted a retrospective study of data on women who were eligible for referral to follow-up during the period from February 1996 through August 2000. Based on published findings on underserved women, we selected three effectiveness cutoff points for each subpopulation: an 80% contact and notification rate and a 72% referral appointment rate for system effectiveness and a 60% appointment/treatment compliance rate for system performance.

Predictors of system effectiveness and performance included measures investigated in previous studies: race/ethnicity, patient age, co-existence of an STD, and type of patient visit (family planning, maternity, walk-in, STD). To establish internal benchmarks, the number of prior follow-up referrals and the HDHHS health center attended were also determined.

The study was approved as a quality assurance measure by HDHHS and approved by the UT Health Science Center at Houston Committee for the Protec-

tion of Human Subjects. Data were analyzed without identifiers.

Study population and practice settings

HDHHS health centers function as the health safety net for the city of Houston, providing preventive services to underserved and underinsured populations. The Department operates seven neighborhood health centers and one walk-in center that draw clients from the metropolitan area. The health centers draw clients from minority communities (85% of clients are identified as Hispanic and/or African American), with an estimated 33% of clients living below the poverty level. Most clients have no form of medical insurance. Demographic profiles of the service areas of the seven health centers are presented in Table 1.

Eighty-three percent of visits by women are for family planning services. HDHHS provides free Pap smear screening, which is covered under Title V, Title XIX, and Title XX, or applies a sliding scale fee. Fees range from \$2 to \$20, depending on family income and the number of dependents.

From February 1996 through August 2000, 89,061 women ages 13 or older were screened for cervical cancer at the family planning, maternity, or STD clinics operated by the health centers. Of these women, 8,275 (9.3%) had abnormal cytology findings, triggering follow-up by either health center staff (5,534, or 66.9%) or Central Office staff (2,741, or 33.1%). Women to be scheduled for follow-up by Central Office staff are the subjects of this investigation.

Table 1. Demographic profiles of service areas of Houston Department of Health and Human Services neighborhood health centers

Characteristic	Center N Percent	Center W Percent	Center C Percent	Center L Percent	Center M Percent	Center R Percent	Center S Percent
Race/ethnicity							
Non-Hispanic white	16.0	53.0	16.5	2.9	10.2	13.3	7.7
African American	51.4	9.7	9.8	57.2	3.4	67.0	83.2
Hispanic	32.0	35.6	72.6	39.3	84.6	17.1	7.8
Other	0.1	1.7	1.1	0.6	1.8	2.6	1.3
Age 15–44 years	21.9	23.8	21.9	21.1	22.8	23.5	23.1
High risk of sexually transmitted disease	24.8	25.5	25.6	23.6	28.9	27.8	24.1
Below poverty level	32.6	22.7	35.5	39.6	33.6	37.1	29.6
Single, female head of household	34.9	25.1	27.5	42.9	22.0	50.9	45.3

HDHHS patient management protocols

All Pap smear tests were analyzed by the Texas Department of Health's Women's Health Laboratories in San Antonio, and test results were sent directly to the HDHHS Central Office for processing and handling. The original laboratory reports were returned to the health centers for inclusion in the patients' medical records; copies of the test results on all women with abnormal smears were kept in Central Office files.

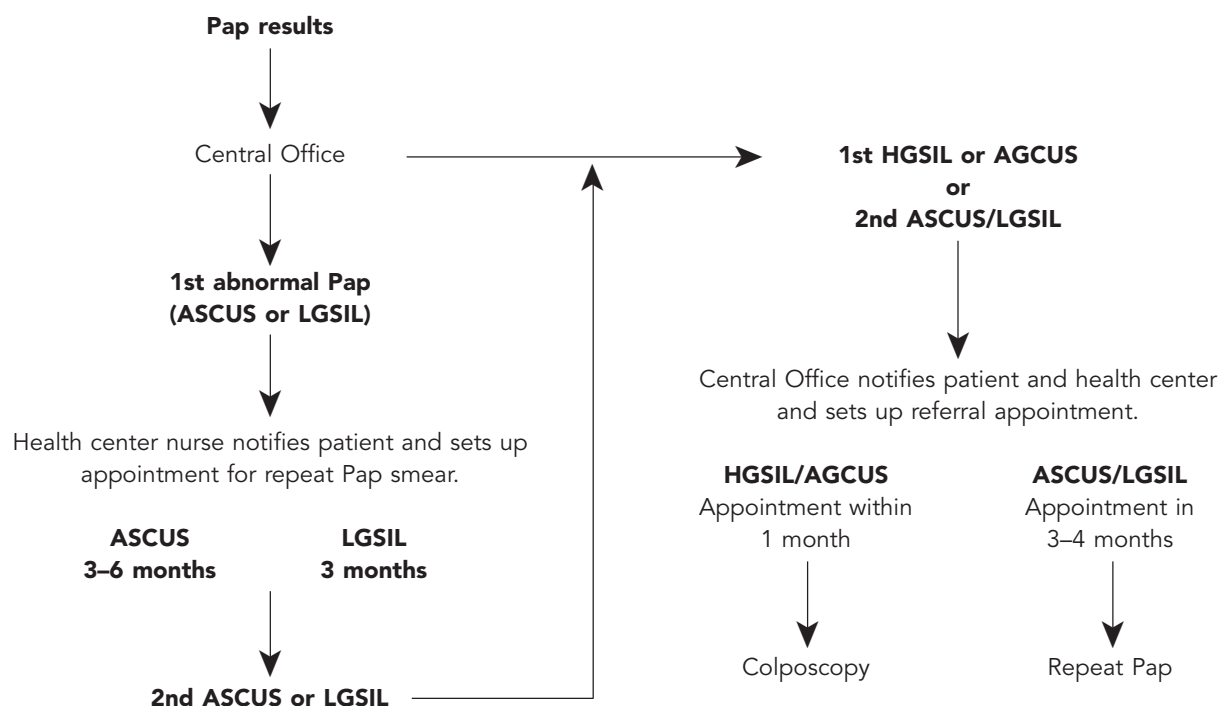
Following the Bethesda System, cervical abnormalities include (by degree of severity) ASCUS, LGSIL, HGSIL, and AGCUS. More severe findings (carcinoma in situ and invasive cancer) trigger a different protocol. See the Figure for the algorithm used in the Central Office follow-up process.

Two bilingual female staff members were assigned solely to Pap smear follow-up and referral. A minimum of three telephone attempts were made to inform patients of abnormal results. If these attempts were unsuccessful, a letter written in simple language in either English and Spanish was mailed to the last known address, requesting a return call to inform the patient of her laboratory test results. If the patient was successfully contacted, an appointment confirmation letter (in either English or Spanish) was sent. The

letters emphasized the importance of obtaining further diagnostic evaluation and provided information about obtaining a Harris County Hospital District gold card to avoid being charged for the service if eligible. Potential fees were mentioned in the letters.

All follow-up activities were documented in each woman's file at the Central Office. The file included a diary of all notification attempts, appointment dates, requests for information, and any returned correspondence. Notes on the reason for refusing an appointment were recorded. These included having met the eligibility requirements of the Harris County Hospital District and opting to be seen at a county facility, having private insurance or a Medicaid card and preferring to be seen by a private physician, and being pregnant and wanting to postpone the appointment until after delivery. In the case of pregnant women, the delivery date was recorded and the file tagged for later contact. Central Office staff notified the health centers of those women who could not be reached, and their medical records were flagged for immediate attention in the event they returned for medical care. Health centers were also notified of referral appointment dates and times for inclusion in the women's medical records.

Figure. Abnormal Pap smear screening follow-up procedures used by Houston Department of Health and Human Services Central Office, February 1996–August 2000



A non-health department clinic was used to follow up patients who had abnormal findings that required more intensive screening procedures. The staff at this referral clinic was responsible for the care and follow-up of referred patients (for example, rescheduling patients if appointments were not kept). The referral clinic provided care through treatment and follow-up. Two to four years could elapse before a patient was released from a referral clinic and her medical record mailed to the HDHHS Central Office for distribution to the appropriate health center.

Data collection and analysis

The Medical Director of Women's Health Laboratories provided a computer file of all cytology results on Pap smears sent for analysis by the HDHHS health centers during the study period. The dataset included information on client demographics; cytology results; other findings (adequacy of smear, presence of an STD); center identification; clinic identification (family planning, maternity, walk-in, or STD); and laboratory recommendations. HDHHS protocol guidelines were used to identify women for health center follow-up and Central Office referral.

Central Office files were sampled systematically for review. The sampling process took into account the lag time in receiving follow-up information from the referral clinics and the two to four years that could elapse before the client was released. Data on contact history and referral appointments were extracted from the log cards in each client's file and entered into the laboratory database. Compliance was determined by file documentation that the woman had completed the referral evaluation or was continuing to be evaluated and/or treated. Appointment data were entered into the laboratory database as two variables: show or no show. Women were classified as "no shows" if they had not been seen within nine months of the initial appointment date and were therefore assumed to be lost to follow-up.

SPSS 10.0 was used to analyze the dataset.²² We calculated chi-square statistics, odds ratios, and confidence intervals to determine the representativeness of the sample and identify possible associations between the variables of interest, referral acceptance, and show vs. no-show behavior.

RESULTS

There was no significant difference between those sampled ($n = 1,216$) and those not sampled ($n = 1,525$) in terms of race/ethnicity, age, history of STD, severity of abnormality, or number of prior referrals. There

was no significant difference in health center attended when this indicator was adjusted race/ethnicity. The racial/ethnic composition of those attending HDHHS health centers and eligible for referral did differ from the HDHHS demographic profile: 60.6% were categorized as Hispanic, 35.9% as African American, and 3.5% as "other."

System effectiveness

Of the 1,216 women sampled, 290 (23.8%) had been referred for HGSIL/AGCUS follow-up, and 926 (76.2%) were referred for ASCUS/LGSIL follow-up. Central Office staff were successful in notifying 1,169 (96.1%) women of their abnormal test results, 885 (95.6%) with ASCUS/LGSIL findings and 284 (97.9%) with HGSIL/AGCUS (Table 2). There was no evidence to suggest that race/ethnicity was a significant factor at the patient notification stage.

Of the 1,169 women initially contacted, 103 (8.8%) were lost to follow-up after notification of their test results and 80 (6.8%) declined the referral appointment, opting to see a private physician or go a county clinic. As there was no file documentation that these 80 women scheduled private appointments, they were also considered lost to follow-up.

Referral appointments were scheduled for 986 women, 79.6% for ASCUS/LGSIL evaluation and 85.5% for HGSIL/AGCUS evaluation (see Table 2). Among women with ASCUS/LGSIL, African American women were 53% less likely to schedule an appointment for follow-up evaluation than other women. Among those with HGSIL/AGCUS, there was no significant difference across the three racial/ethnic groups in appointment-setting behavior.

There was no evidence of an association between appointment-setting behavior and the co-existence of an STD, health center attended, or number of prior referrals. There did appear to be a significant association with age and type of patient visit (Table 3). Among women with ASCUS/LGSIL who were >31 years of age, African American women were 79% less likely than women identified as Hispanic or "other" to schedule an appointment. African American women were also less likely than women in the other two groups to set up an appointment if referred following a family planning (50% less likely) or maternity visit (85% less likely).

System performance

According to the study criteria, to be designated "compliant" a woman needed to receive further screening and/or treatment within nine months of her initial appointment. Of the 986 women scheduled for follow-

Table 2. System effectiveness and performance by severity and race/ethnicity

Characteristic	Referral base	Percent contacted	Percent scheduled	Percent compliance
ASCUS/LGSIL				
African American	358	92.7	76.5 ^a	47.6 ^b
Hispanic	539	97.9	87.7	63.0
Other	29	86.2	80.0	45.0
Total number	926	885	737	422
HGSIL/AGCUS				
African American	78.0	100.0	83.3	66.2
Hispanic	199.0	98.0	89.7	78.9
Other	13.0	84.6	81.8	55.6
Total number	290	284	249	185
Total number	1,216	1,169	986	607
Percent	100.0	96.1	84.2	61.5

^a $\chi^2 = 17.490$; $p < 0.001$; OR = 0.472; 95% CI 0.330, 0.674

^b $\chi^2 = 14.600$; $p < 0.001$; OR = 0.550; 95% CI 0.405, 0.748

ASCUS = atypical squamous cells of undetermined significance

LGSIL = low-grade squamous intraepithelial lesions

HGSIL = high-grade squamous intraepithelial lesions

AGCUS = atypical glandular cells of undetermined significance

OR = odds ratio

CI = confidence interval

up evaluations, 607 (61.5%) were compliant (Table 2). Of the 737 women with ASCUS/LGSIL, 422 (57.3%) appeared for care within the nine-month time frame. Of the 249 women with HGSIL/AGCUS, 185 (74.3%) were seen within the time period.

Consistent with appointment-scheduling behavior, African American women were 45% less likely than Hispanic or "other" women to keep their appointments and/or receive care for ASCUS/LGSIL (Table 2). Among those with HGSIL/AGCUS who were 21–25 years of age, African American women were 73% less likely than women in the two other racial/ethnic groups to comply with follow-up care (Table 3). They were also 59% less likely than women in the Hispanic and "other" categories to comply following a family planning visit. There was no evidence of an association between compliance and co-existence of an STD, number of prior referrals, or health center attended.

CONCLUSION

This study was designed to systematically evaluate HDHHS's centralized referral process for women with abnormal Pap smears and establish baseline measure-

ments of system effectiveness and performance. Two measures were used to determine system effectiveness: an 80% success rate in initial contact notification and a 72% success rate in scheduling appointments. The measure of performance was a 60% rate of referral compliance. These measures were chosen as cutoff measures because they were the indicators and the average rates reported for control groups in experimental studies evaluating interventions to improve abnormal Pap smear follow-up compliance.^{2,7,9,11,16,17} The results of the present study show that the Department was able to exceed the effectiveness measures that had been established for contact (95.6% for ASCUS/LGSIL and 97.9% for HGSIL/AGCUS) and appointment setting (79.9% for ASCUS/LGSIL and 85.5% for HGSIL/AGCUS). Follow-up compliance (61.5%) for all of the scheduled patients also met the performance cut-off points. However, women with less serious findings fell below the cut-off point (57.3%, compared with 74.3% for HGSIL/AGCUS).

African American women in certain age groups or receiving certain services were less likely than other women to obtain further diagnostic services, suggesting that more intensive services may be needed for

Table 3. Appointment scheduling compliance by race/ethnicity, age, and type of visit

Characteristic	ASCUS/LGSIL		HGSIL/AGCUS	
	Appointments scheduled	Compliance	Appointments scheduled	Compliance
African American women: age in years				
≤ 21	112	55	11	7
> 21 ≤ 25	63	24	20	9 ^a
> 25 ≤ 31	47	28	19	17
> 31	32 ^b	14	15	10
African American women: type of patient visit				
Family planning	222 ^c	105	55	36 ^e
Maternity	9 ^d	5	6	4
Walk-in	3	0	3	2
STD	20	11	1	1
Hispanic women: age in years				
≤ 21	101	50	21	15
> 21 ≤ 25	125	87	25	18
> 25 ≤ 31	129	84	44	36
> 31	108	71	85	69
Hispanic women: type of patient visit				
Family planning	380	242	145	121
Maternity	67	38	19	11
Walk-in	11	8	7	5
STD	5	4	4	1
Other race/ethnicity: age in years				
≤ 21	8	3	2	0
> 21 ≤ 25	2	1	1	1
> 25 ≤ 31	4	2	2	2
> 31	6	3	4	2
Other race/ethnicity: type of patient visit				
Family planning	15	6	8	3
Maternity	1	0	1	2
Walk-in	1	1	0	0
STD	3	2	0	0

^a $\chi^2 = 5.774$; $p < 0.016$; OR = 0.265; 95% CI 0.087, 0.805^b $\chi^2 = 16.798$; $p < 0.001$; OR = 0.207; 95% CI 0.094, 0.458^c $\chi^2 = 11.706$; $p < 0.001$; OR = 0.495; 95% CI 0.330, 0.744^d $\chi^2 = 16.300$; $p < 0.001$; OR = 0.150; 95% CI 0.056, 0.401^e $\chi^2 = 6.707$; $p < 0.01$; OR = 0.406; 95% CI 0.203, 0.813

OR = odds ratio

CI = confidence interval

these women. As a result, a case management function has been established at the Central Office and at the neighborhood health centers to follow up patients with the given characteristics.

In addition, the study showed that a substantial number of women were lost to follow-up in the referral to the non-health department clinic. To deal with

this problem, HDHHS has begun exploring the possibility of contracting with community providers located near the neighborhood health centers. The results also indicate a need to develop targeted health education measures for subpopulations that stress the importance of further evaluation when abnormal Pap smear results are found. Redesign of current education

programs will be based on a series of focus groups conducted with women from subpopulations at risk of being lost to follow-up.

This study also emphasizes the importance of cooperative studies being conducted by a local health department and a school of public health. People from both settings have unique knowledge and skills that can be applied to problems of public health concern. The local health department provides a rich environment for faculty research and the training of students. The health department can exploit the research skills of faculty and the work force that can be provided by students. The result of such collaboration can be a synergy that enhances the services of the health department and improves patient care for the underserved.

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