

The Burden of Cervical Cancer in Minority Populations: Effective Strategies in Reducing Disparity

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Abstract

Significant declines in the incidence and mortality rates of cervical cancer have occurred in the United States since the introduction of the Papanicolaou test. Unfortunately, a reduction in the burden of cervical cancer is not equal across all ethnic and racial groups; significant disparities exist. Disparities are reflected not only in mortality and incidence rates, but also in screening rates. Barriers to screening and effective approaches towards overcoming them are reviewed in this manuscript. As minority populations increase over the next few decades, it becomes ever more urgent to employ interventions to reduce the burden of cervical cancer among diverse groups.

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INTRODUCTION

Cervical cancer is the second most common cause of cancer worldwide, with an estimated 500,000 cases and 250,000 deaths per year. ¹ In the United States (US) in 2008, an estimated 11,070 women will be diagnosed with cervical cancer, and approximately 3,870 women will die from the disease. ² The decline in US incidence and mortality rates can largely be attributed to implementation of the Papanicolaou (Pap) test. However, marked disparities in these rates persist despite overall reductions (Table 1). ³ Incidence and mortality rates for Hispanic and Asian women may be even higher than reported, as speculation exists that these women return to their countries of origin to receive “traditional” treatments, or to die. Women without legal status who do not seek medical help are not reflected in these data.

Figure 1

Table 1: Average annual rates and lifetime risks associated with cervical cancer in the US, by racial and ethnic group.

	SEER ^a Average Annual Incident Rates ^a	Average Annual Mortality Rates ^b	% Lifetime Risk of Diagnosis ^c	% Lifetime Risk of Dying ^c
Non-Hispanic White	7.2	2.2	0.67	0.21
Black	11.4	4.9	0.92	0.43
Hispanic	13.8	3.3	1.19	0.35
Asian American/Pacific Islander	8.0	2.4	0.76	0.32

^a Per 100,000 persons, 2000–2004, age-adjusted; calculated from 17 SEER areas ^b Per 100,000 persons, 2000–2004, age-adjusted; calculated from data provided by the National Center for Health Statistics ^c 2002–2004 *Surveillance Epidemiology and End Results

Over the next few decades, minority groups are expected to increase in size and comprise a larger percentage of the US population. By 2050, it is estimated that the Hispanic population will comprise 24.4% of the US population (up from 12.6% in 2000). ⁴ Similarly, the African American and Asian populations are projected to rise from 12.7% and 3.8%, respectively, of the population in 2000 to 14.6% and 8%, respectively, in 2050. ⁴ Persistent health disparities coupled with growing population sizes will lead to increased burdens on the US healthcare system, and significantly impact the societal infrastructure of these communities.

REASONS FOR DISPARITY

Observed disparities can be partially attributed to differences in screening practices, particularly for Hispanics and Asian Americans. Screening rates for Hispanic and Asian American women may be underreported if surveys are administered in English.⁵ Analyses of studies that examine barriers to screening indicate that the major barriers are cultural/personal, socioeconomic, and system-based. Many of the barriers are also factors in nonadherence to follow-up procedures when an abnormal Pap test is identified.

CULTURAL AND PERSONAL BARRIERS

For Hispanic and Asian American women, low levels of acculturation, lack of English proficiency, and foreign birth are highly associated with nonadherence.^{6,7,8,9} Personal barriers include dislike for physical exams, fear of finding cancer, embarrassment, and pain.^{6,10,11,12} Many noncompliant minority women believe that Pap smears are only necessary when symptoms are present.¹³ Many believe that the development of cancer is bad luck and they do not want to know if they have it.¹⁴ Women who do not get screened often cite that they do not get tested because others will think they are sexually active; if they are not sexually active, they believe they do not need to be screened.^{15,16}

SOCIOECONOMIC BARRIERS

Lack of adequate healthcare insurance is a significant factor in screening practices.² Low income and lack of medical insurance are also major barriers to Pap screening among Hispanic and African American women.¹⁷ These barriers are also common in other racial/ethnic groups.^{5,10,11}

A meta-analysis found that socioeconomic deprivation is a strong predictor of receiving screening, diagnosis, treatment, and survival odds.⁹ Low socioeconomic status correlates with later stage of diagnosis among African American women.¹⁸ Low levels of education are also reliable indicators for screening nonadherence.^{8,10} Finally, when survival rates for cervical carcinomas were compared among 1,553 Caucasian and African American women in the military healthcare system, no differences were observed. In this scenario, cost, health insurance, and other racially related barriers did not exist.¹⁹

SYSTEM-BASED BARRIERS

Many minority women rely on their healthcare provider to instruct them about preventive medical care. This is exemplified by the strong association between physician recommendation and having had a recent Pap smear.^{5,7,11,12}

Women who admit that no healthcare provider ever told them that they need a Pap test are half as likely to report a current screen.²⁰ For all racial and ethnic groups, there is a strong link between continuity of care and routine screening.^{6,21,22}

Health access barriers include long wait times at health clinics and a lack of transportation, family support, or available child care.^{6,14,22} For those in managed care, many barriers are related to insurer or provider factors, such as long wait times and difficulty obtaining appointments.²¹ Hispanics are more likely than non-Hispanic whites to have no usual source of care, long wait times, difficulty obtaining care, and communication problems with their healthcare provider.²¹ Asian Americans are more likely to report dissatisfaction with quality of care.²¹

LACK OF KNOWLEDGE REGARDING HUMAN PAPILOMAVIRUS, CERVICAL CANCER, AND SCREENING

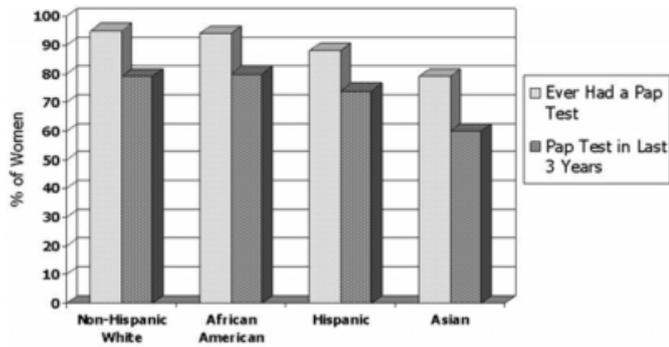
Another contributing factor to screening practices is a woman's level of knowledge regarding human papillomavirus (HPV), its link to cervical cancer, and Pap tests. Women who have never had a Pap test are more likely to say that they did not know they could get cervical cancer (adjust OR 2.6; 95% CI, 1.1 to 6.4)¹⁴ and often report not knowing where to go for the test.¹⁵ A greater percentage of Hispanic women, compared with non-Hispanic white women, are not aware of the Pap test.⁶ Chinese American women have a low level of knowledge regarding Pap tests, which is related to their degree of fluency in English.²³ Female Hispanic immigrants may not be aware of the connection between HPV and cervical cancer, and have little knowledge about cervical cancer and its etiology.¹³

DIFFERENCES IN TREATMENT

Disparity in the mortality rate for African Americans, which is twice that of non-Hispanic whites, may be partially due to differences in treatment, as screening rates are similar (Figure 1). African Americans are less frequently treated for cervical cancer, or are treated inappropriately, despite later stages of diagnosis.^{24,25} Based upon data for over 2,300 women, African American and Hispanic women over the age of 35 years diagnosed with stage IA2 cervical cancer are less likely to be treated with a hysterectomy than their white counterparts.²⁶ Additional factors that may contribute to disparities in treatment include co-morbid conditions, poorer health, a patient's refusal of treatment, and lack of physician-recommended treatment.²⁴

Figure 2

Figure 1: Cervical cancer screening practices, by racial and ethnic group.



APPROACHES TO REDUCING DISPARITIES IN CERVICAL CANCER

Many projects have been launched at the federal, state, and local levels to reduce cervical cancer-related disparities. Such methods involve federal funds to provide aid to increase screening awareness and assist minorities in accessing healthcare; create community partnerships to educate healthcare providers and community leaders and provide outreach; provide culturally-appropriate educational materials to at-risk populations; use lay-healthcare workers to educate and guide women; and make telephone calls to remind women to get screened or to follow-up on abnormal Pap tests.

NATIONAL INITIATIVES

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides screening to uninsured or underinsured women, at or below 250% of federal poverty level, aged 18 to 64 years. This represents approximately 8% to 11% of women in the US. In 2005, 6.7% of all eligible women had a Pap test through this program. From 1991 to 2005, there was an 81.2% increase in the total number of women who received Pap tests through the NBCCEDP.^{27,28} In 2001 and 2002, only 14% of women who received a Pap test were African American, 23% were Latina, and 5% were Asian American/Pacific Islanders.²⁷ The program has increased screening among low-income women; however, disparities in screening behaviors persisted after the program had been in place for five years.¹⁷

A second federally-sponsored program is the National Cancer Institute's (NCI's) Patient Navigator Academy. Patient Navigators help patients overcome barriers to care by helping them “navigate” the healthcare system and provide patients with an opportunity to receive timely diagnosis and treatment. Navigators help schedule appointments,

coordinate insurance, participate in community outreach programs, form community partnerships, and encourage clinical trial participation.²⁹

COMMUNITY-BASED INITIATIVES

PARTNERSHIPS

Partnerships between federal agencies and community groups provide considerable support for community-based outreach programs. This is exemplified by the Racial and Ethnic Approaches to Health (REACH) 2010 program.³⁰ REACH 2010 provides support to community coalitions as they design, implement, and evaluate community-driven strategies to eliminate racial and ethnic health disparities.³⁰

The Special Populations Network (SPN) is another example of a multi-tiered partnership. This initiative ended in 2005, but the programs were rolled into the Community Networks Program.³¹ The SPN included five national, two regional, and 11 local programs. The major goal was to promote cancer awareness research in minority and underserved communities, targeting most ethnic and racial populations.³² Funding was provided to train minority researchers, develop culturally appropriate education materials, and train lay healthcare workers in target communities.³²

Maryland's SPN (MSPN), a community and academic partnership, utilized evidence-based education interventions such as print and broadcast media, health fairs, tribal and community centers, and sporting events. Baseline screening services and health evaluations were available when appropriate.³³ Behavioral Risk Factor Surveillance System data indicate success in improving positive health behaviors in MSPN target areas with significant increases in Pap test utilization compared with those in non-target areas.³³

Colorado's SPN, the Greater Denver Latino Cancer Prevention/Control Network, was a special project of the Latino/a Research and Policy Center.³⁴ Examples of their outreach efforts include Dia de la Mujer Latina and The Cancer Monologues. Dia de la Mujer Latina, which received both foundation and private funding, was a cultural, family-centered health fair that offered breast and cervical screening to Hispanic women and provided counseling, education, ethnic music, food, entertainment, and giveaways. This venue allowed women to overcome barriers they often face when accessing preventive screening services and culturally appropriate educational materials.³⁴

Similarly, a cooperative effort between the NCI and University of California, Davis, called the Asian American

Network for Cancer Awareness, Research, and Training, targets Asian Americans.³⁵ Its goals are to increase cancer education among the Asian American population, increase research in healthcare disparities, and collect and analyze data regarding its impact in reducing disparities.³⁵

TELEPHONE-BASED INTERVENTION

Community outreach can also be achieved through telephone-based intervention. Telephone counseling results in higher adherence rates to initial colposcopy visits, compared with telephone confirmation only (76% vs. 68%, OR 1.50; 95% CI, 1.04 to 2.17). Telephone confirmation increases the likelihood of compliance (68%) when compared with standard care (no phone call; 50%).³⁶

The Screening Adherence Follow-Up (SAFe) intervention model combines health education, counseling, and systems navigation (to improve communication and access to resources) to improve follow-up among low income Hispanic women.³⁷ Patients at risk are targeted for intervention by a bilingual, bicultural Hispanic peer counselor. Women are notified of SAFe services via telephone and invited to participate in the program. Comparison of follow-up rates revealed significant differences; participants with low-grade cytology had an 83% follow-up rate compared with 58% of non-participants, and 93% of SAFe women with high-grade cytology had follow-up compared with 67% of non-participants.³⁷

LAY-HEALTHCARE WORKERS

One of the most effective methods of community outreach involves the use of lay-healthcare workers. These women, often cancer survivors themselves, are from similar cultural backgrounds as the women with whom they try to communicate. For example, promotoras are Hispanic female cancer survivors who are trained to be health educators in their own communities.³⁸ By sharing information, personal contact, and frequent follow-up reminders, promotoras successfully encourage other women to get screened.³⁸ According to a meta-analysis, clinic-based, promotoras-based, and combined approaches can all increase the use of key preventive health services by Hispanic women, including prenatal care, Pap screening, and immunizations.³⁹

Lay-healthcare advisors effectively increase screening compliance in the Asian American population.⁴⁰ In a randomized, controlled trial among Chinese women in Seattle and Vancouver, interventions via direct mail and contact by multilingual outreach workers significantly

changed screening behaviour.⁴¹ Among Vietnamese women in Santa Clara, California, Pap testing increased significantly when intervention involved a combination of both lay-healthcare worker outreach and media-based education versus education only.⁴²

OTHER APPROACHES

Preventive behaviors can also be increased by targeting healthcare professionals who interact with minority populations. At New York Presbyterian Hospital, a cross-cultural curriculum for residents and medical students has been introduced to increase physicians' "cultural competence," yielding greater communication and understanding between physicians and minority patients.⁴³ Strengthening the relationship between minority women and their physicians can enhance the quality of care and health outcomes, including increased cancer screening. This can also be accomplished by making primary care sites more accessible, linking patients to one physician, organizing primary healthcare centers to provide for all female healthcare needs, and coordinating specialty care.²² All of these factors have been associated with improved patient-physician relationships.²² Reaching out to the community pharmacist may be an effective means for the dissemination of medical information.⁴⁴

VACCINATION

Oncogenic HPV is a necessary cause (99.7%) of cervical cancer.⁴⁵ Of HPV types that infect the genital mucosa, 15 are oncogenic and considered high-risk; oncogenic virus types 16 and 18 account for approximately 77% of all cervical cancer cases in the US. Together, oncogenic types 31, 45, and 52 account for an additional 8% of cervical cancers.⁴⁶

Eighty percent of all women will acquire a genital HPV infection during their lifetime;⁴⁷ at any one time, an estimated 20 million women are infected with genital HPV.⁴⁷ Women with persistent oncogenic virus infections are at a significantly increased risk for developing cervical precancerous lesions and cervical cancer.⁴⁸

Cytological screening can detect precancerous lesions but does not prevent HPV infections. Regular screening for all women is necessary, as progression to cervical cancer can occur 2 to 20 years post-infection.⁴⁹ Vaccination against predominant oncogenic virus types is the only primary means to prevent infection.

Two vaccines have been developed to protect against infection from types 16 and 18, the two most prevalent oncogenic HPV types that cause cervical cancer.⁴⁶ The currently licensed vaccine, Gardasil[®] (Merck and Co.; Whitehouse Station, NJ, US), is designed to protect against oncogenic HPV 16 and 18 and low-risk HPV 6 and 11.⁵⁰ HPV 6 and 11 are rarely responsible for malignancy.⁴⁶ A second vaccine, Cervarix[®] (GlaxoSmithKline Biologicals; Rixensart, Belgium), is designed to protect against oncogenic HPV 16 and 18.⁵¹

Both vaccines are effective at preventing oncogenic virus type 16- or 18-induced persistent infections and cervical intraepithelial neoplasia 2+. Cervarix[®] also demonstrates type-specific cross-protection against persistent infections caused by HPV 31, 45, and 52.⁵² Long-term immunogenicity has been demonstrated for both vaccines; 5.0 years and 6.4 years for Gardasil[®] and Cervarix[®], respectively.^{53,54,55} No serious adverse effects have been reported for either vaccine.^{50,52}

CONCLUSION

The existence of disparities in healthcare for cervical cancer screening and treatment is well recognized, and recent research has focused on identifying and alleviating barriers that create disparities. Minority populations in the US are increasing in proportion at faster rates than the Caucasian population. If disparities persist, the burden of cervical cancer will grow. Culturally appropriate education regarding cervical cancer, its link to oncogenic HPV, and the importance of cervical screening can significantly reduce incidence and mortality rates for all populations. Education should not target only high-risk populations, but also their physicians. Developing culturally-competent physicians can significantly reduce health disparities. Community-based outreach can enhance communication between healthcare providers and underscreened women.

Broad-based implementation of cervical cancer vaccination programs will not eliminate the need for screening, but will reduce the impact of screening disparities on minority populations. Most of the programs discussed above are designed to reduce cervical cancer disparities, and education about cervical cancer vaccination could be incorporated into the programs. Increased utilization of cervical cancer vaccines could provide protection against precancerous lesions and cervical cancer beyond that of current Pap screening.

The dissolution of healthcare disparities in the cervical cancer spectrum, from screening to treatment and subsequent follow-up, will require the implementation of accessible, culturally-competent screening, vaccination, and treatment programs, as well as further research efforts to better understand the factors that contribute to the access and delivery of equitable care across all racial and ethnic groups.

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