

# Ethnic Disparities in Cervical Cancer Illness Burden and Subsequent Care: A Prospective View in Managed Care

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**C**ervical cancer imposes significant clinical and economic burdens on managed care. More than 11,000 cases of invasive cervical cancer and 40,000 in situ cases are diagnosed annually in the United States, costing an estimated \$4.6 billion each year.<sup>1,3</sup> Although death rates have declined for the past 50+ years, invasive cervical cancer claims the lives of more than 4000 women in the United States each year and remains a serious concern.<sup>3</sup>

## Cervical Cancer Incidence and Mortality by Ethnicity

Data on the incidence of invasive cervical cancer and related mortality rates delineated by ethnic group within the United States highlight the disparate nature of this cancer. The cumulative, age-adjusted incidence ratio of invasive cervical cancer is 8.7 per 100,000 US women. The rate of invasive cervical cancer in African American and Hispanic populations is significantly higher than the national average, at 11.4 and 13.8 per 100,000 women, respectively.<sup>4</sup> Conversely, American Indian/Alaskan Native women have a lower than average incidence rate of 6.6 per 100,000 women. The incidence rates for whites and Asian/Pacific Islanders approach the cumulative average, at 8.5 and 8.0 per 100,000 women, respectively (Figure 1).<sup>4</sup> More specific ethnic analyses demonstrate that Vietnamese women aged 30 to 54 years have the highest incidence of invasive cervical cancer and are 5 times more likely to develop the disease than Chinese women aged 30 to 54 years, who have the lowest incidence overall.<sup>5</sup>

Variations in cervical cancer mortality rates among ethnic groups are often similar but not parallel to the differences in incidence rates. Although Hispanic women had the highest incidence of cervical cancer according to Surveillance Epidemiology and End Results (SEER) 2007 estimates, the mortality rate for Hispanic women with cervical cancer was 3.3 per 100,000 women, the third highest of the ethnic groups evaluated. Black women had a mortality rate of 4.9 per 100,000 women, and American Indian/Alaskan Native women had a mortality rate of 4.0 per 100,000 women.<sup>4</sup> The high rate of mortality for American Indian/Alaskan Native women appears contradictory to their low estimated incidence of cervical cancer. Whites and Asian/Pacific Islanders had a mortality rate that was

### Abstract

Costs associated with cervical neoplasia and cancer impose a significant burden on managed care. More than 50,000 cases are diagnosed annually in the United States, accumulating ~\$4.6 billion in costs per year. The apparent disparity of care related to screening and treatment among specific ethnic groups and economically disadvantaged subpopulations results in elevated cervical cancer mortality rates and adds to managed care's burden. This is likely the result of several factors, including differences in the stage of cervical cancer at diagnosis, cultural barriers to undergoing regular cervical screening, and impaired access to follow-up care after receiving abnormal Papanicolaou smear test results.

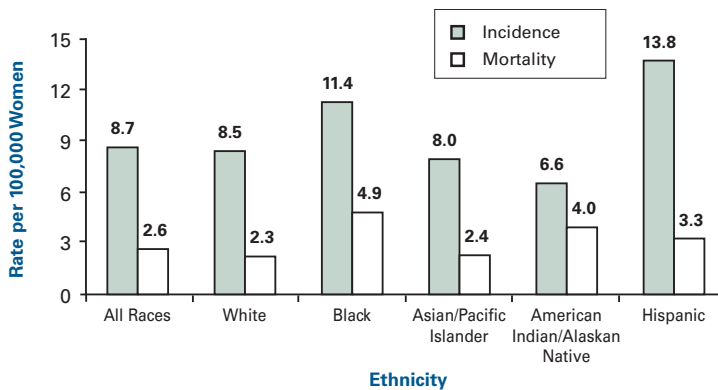
To overcome socioeconomic and cultural barriers to providing adequate care for patients with cervical cancer, the implementation and effectiveness of secondary prevention methods should be revisited and options for primary prevention, such as human papillomavirus vaccination, should be explored.

Vaccines have the potential to reduce disparities in care, particularly if they are provided to economically disadvantaged women or those whose culture serves as an obstacle to obtaining appropriate care. If action is not taken to broaden access to vaccines, it is likely that managed care will continue to bear the burden of increased costs due to poor outcomes.

(*Am J Manag Care. 2008;14:S193-S199*)

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**Figure 1.** Cervical Cancer Incidence and Mortality Rates by Ethnicity (SEER 2000-2004)



SEER indicates Surveillance Epidemiology and End Results. Source: Reference 4.

consistent with the cumulative average of 2.6 per 100,000 women, which corresponded to their incidence rates (Figure 1).<sup>4</sup>

The varying incidence and mortality rates for cervical cancer across different ethnic groups can be explained by a number of factors. There are potential differences in the quality of data obtained for specific ethnic subpopulations.<sup>6</sup> Other factors relate to secondary prevention and follow-up care.<sup>7</sup> Some women lack adequate financial resources to obtain appropriate cervical screening to detect precancerous lesions or cancer in its early stages or to secure follow-up care. This explains some variance in incidence and mortality rates. For example, higher than average cervical cancer deaths have been observed in women living in economically disadvantaged areas, such as Hispanic/Latina women living on the Texas–Mexico border and white women living in Appalachia.<sup>8</sup>

In women living in certain demographic areas, the incidence of cervical cancer is low but mortality rates are high—a discrepancy that may be attributable in part to a lack of regular screening (precluding the detection of invasive cervical cancer until its later stages) or differential follow-up care. Some women in certain ethnic demographics may fail to undergo screening because of cultural or religious reasons.<sup>8</sup>

Barriers to secondary prevention methods and adequate follow-up care lead to poorer diagnostic outcomes and rising treatment costs for cervical

cancer patients in managed care. The rising costs are primarily attributable to the greater number of women in certain subpopulations receiving a diagnosis of cervical cancer in its later stages and the correspondingly higher mortality rate. The only way to address the disparity of care in cervical cancer screening and treatment across different ethnic groups is to identify and remedy barriers to appropriate screening and treatment.

### Cervical Screening

Data demonstrating a nearly 100% cure rate for cervical dysplasia that is detected early have justifiably spurred the implementation of screening initiatives in managed care.<sup>9</sup> The National Committee for Quality Assurance’s State of Healthcare Quality 2006 report estimates that ~80 percent of women aged 21 to 64 years enrolled in a health plan had at least 1 Papanicolaou smear test (Pap test) between 2003 to 2005.<sup>9</sup> The national cytologic screening rate in commercial plans rose from ~70% in 1996 to ~80% in 2005. These figures represent plan populations overall and are not stratified by ethnicity.<sup>9</sup>

**Ethnic Variations.** As the Centers for Disease Control and Prevention (CDC) DATA2010 database demonstrates, cervical screening rates can vary significantly according to ethnic group.<sup>10</sup> In 2005, age-adjusted rates for women who underwent a Pap test within the previous 3 years were highest for non-Hispanic black women and white women, at 80% and 79%, respectively.<sup>10</sup> Hispanic/Latina women reported relatively lower Pap test screening rates (74%), and American Indian/Alaskan Native and Asian/Pacific Islander women had the lowest 3-year Pap test screening rates, at 71% and 64%, respectively (Figure 2).<sup>10</sup>

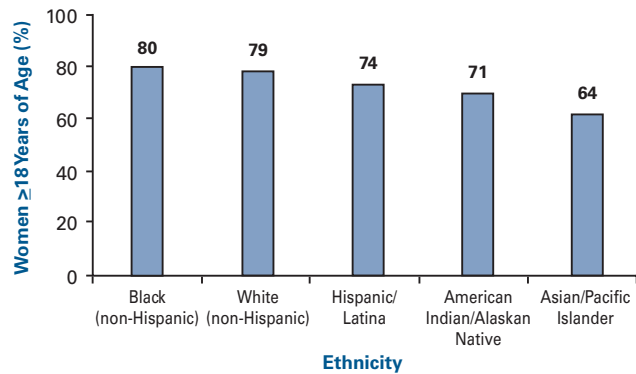
These screening rates raise interesting questions when considered alongside current mortality data. Populations that have higher screening rates might be expected to have higher diagnostic rates of early and more curable stages of cervical neoplasia and correspondingly lower mortality rates. However, blacks have the highest cervical screening rates but also the highest cervical cancer mortality rates. Conversely, Asian women have one of the lowest rates of cervical screening of all ethnic groups yet have a relatively average cervical cancer mortality rate. Differential access to and use of

follow-up care in these groups may help explain this dichotomy.

**Racial, Cultural, and Personal Factors.** Several factors may help explain the disparate rates of women who undergo Pap test screening among the various ethnic groups. Screening rates can be affected by racial or cultural factors, such as modesty, fatalism, and prohibitions against examination by male healthcare providers. Women may have competing life priorities and, in some cases, may not perceive screening as having equal importance when compared with income generation or work and familial responsibilities.<sup>7,8</sup> Little data exist to document what precise cultural phenomena drive lower screening rates in particular ethnic groups, although studies have targeted specific populations. To gain a better understanding of the relatively low rate of Pap test screening among Hispanic women, Byrd et al conducted 13 focus groups consisting of 84 Hispanic women aged 18 to 61 years.<sup>11</sup> Participants reported embarrassment, fear, and pain as personal barriers to undergoing cervical screening.<sup>11</sup> Differences in sexual behavior may also play a role, because those sexually active women who are at increased risk for human papillomavirus (HPV) infection may feel more anxiety and fear regarding cervical screening.

**Language Barriers.** Language barriers might lead to lower screening rates in some ethnic minorities.<sup>12</sup> In a cross-sectional analysis of 3-year Pap test screening rates, Ponce et al found that Spanish-speaking women who were interviewed by their clinicians in Spanish were 1.7 times more likely to receive a Pap test than those interviewed in English.<sup>12</sup> The impact of language barriers on cervical cancer screening might also be evident when examining Pap test rates stratified by immigration status.<sup>13</sup> The American Cancer Society reported that 80.3% of women born in the United States received a Pap test in the past 3 years, compared with 73.3% of immigrants who have been in the country for more than 10 years and 63.7% of immigrants who have been in the country for less than 10 years.<sup>13</sup> A cross-sectional analysis of the 2000 National Health Interview Survey<sup>14</sup> found that noncitizens were 11% less likely than US-born women to report having undergone a Pap test in their lifetime.

■ **Figure 2.** US Pap Test Rates During the Previous 3 Years by Race for Women ≥18 Years of Age (CDC, 2005)



Pap indicates Papanicolaou smear; CDC, Centers for Disease Control and Prevention.

Source: Reference 10.

**Economic Factors.** Socioeconomic status also appears to contribute significantly to the variance in cervical screening rates for different groups of women. The CDC's DATA2010 database reports the highest screening rates in women whose families have middle and high incomes (81%) and lower rates for those whose families have near poor (71%) and poor (68%) income levels.<sup>10</sup> A 1994 survey that used data from the US National Health Interview found that women living in a household with an income of >\$45,600 were nearly twice as likely to have undergone a Pap test in the preceding 2 years than women with a household income <\$45,600 (odds ratio [OR], 1.9; 95% confidence interval [CI], 1.6-2.2).<sup>15</sup> Similarly, Pap test screening rates for 3568 Hispanic women in the previous 3 years were 76.7% for those with a household income <\$15,000, compared with 90.9% for those with a household income of ≥\$50,000.<sup>16</sup> Considering that this latter Pap test rate is much higher than the national average rate for Hispanic/Latina women, higher economic status appears to be associated with more frequent screening.

Other economic factors may be responsible for the lower cervical cancer screening rates in selected populations. Among 4682 Californian women, late-stage cervical cancer was diagnosed more frequently in 51% who were Medicaid-insured and 42% without Medicaid coverage.<sup>17</sup> The more frequent diagnosis of late-stage cervical cancer in the government-insured patients could indicate that these

economically disadvantaged women did not receive appropriate cervical screening.

The literature asserts that lower levels of education are associated with lower socioeconomic status, and women with lower levels of education are reportedly less likely to be screened than those with higher levels of education.<sup>10</sup> In a study of 3568 Hispanic women residing near the US–Mexico border, women who had less than a high school education were found to have a lower rate of Pap test screening in a 3-year period (77%) compared with Hispanic college graduates (87%). National data from the CDC across all ethnic groups demonstrate consistent results, with 3-year Pap test rates of 68% for women with less than a high school degree, 76% for women with a high school degree, and 83% for women who had at least some college education.<sup>10</sup> The positive association between a higher level of education and higher socioeconomic status suggests that the relationship between educational and economic status is important when determining the likelihood that a woman will undergo cervical screening.

Health insurance coverage is another factor potentially linked to income that appears to affect cervical cancer screening rates. As might be expected, uninsured women had a lower 3-year Pap test screening rate (61.0%) than women with coverage (82.2%).<sup>13</sup> Other studies, however, have found that insurance coverage has little effect on screening rates beyond its relationship to income level. Exploring this further, Katz and Hofer compared the disparity in screening rates between high- and low-income groups observed in data from US patients with data from patients in Ontario, Canada, where healthcare coverage is universal. Despite having universal health insurance, women in Ontario with incomes >\$45,600 were 1.7 times more likely to undergo Pap test screening in a 3-year period than women with incomes <\$45,600 (95% CI, 1.3–2.1).<sup>15</sup> Given the similar results using US data and Canadian data, a woman's income level, independent of insurance coverage, appears to have a greater impact on the likelihood that she will undergo cervical screening.

### Barriers to Follow-up Care

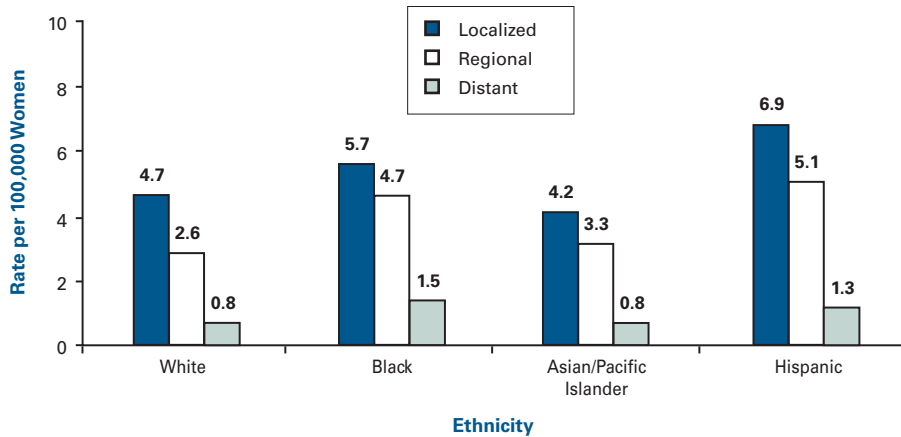
Cervical screening alone cannot sufficiently address the mortality, clinical, and economic bur-

dens associated with cervical cancer on managed care. Adequate follow-up care, in the form of additional screening and, ultimately, treatment, is crucial if lives are to be saved. Even women who undergo Pap test screening are not guaranteed to receive follow-up care (such as colposcopy/biopsy or other treatment) in the event of an abnormal test result.

Several patient characteristics have been identified as risk factors for a lack of access to follow-up care in cervical cancer after receiving abnormal Pap test results or a cervical cancer diagnosis. These include the patient's age, race or ethnicity, and primary language; pregnancy status; income, insurance coverage, or cost for follow-up care; Pap test or health literacy; severity of the lesion; psychological barriers, including fatalism, health beliefs, and embarrassment; and available social support, such as a spouse or live-in partner.<sup>7,18</sup> In relation to ethnic disparities in cervical cancer follow-up care, the most notable factors are the patient's income, insurance coverage, and the cost of follow-up care; primary language; Pap test and health literacy; and psychological barriers.

Women in the United States whose primary language is not English encounter barriers to follow-up care, particularly those in urban populations.<sup>19</sup> Literature reviews report that among non-English-speaking women, those who have higher incomes or private insurance are more likely to adhere to follow-up recommendations.<sup>7,18</sup> Although similar proportions of privately insured and Medicaid patients often receive the recommended follow-up care for cervical cancer, women who have private insurance appear to have a much higher probability of receiving recommended follow-up care than those who lack private insurance (65% vs 60%, respectively).<sup>20</sup> Women with lower levels of health literacy also have been found to receive suboptimal follow-up care.<sup>7,18</sup> For example, women who did not understand the purpose of Pap tests or follow-up care procedures were less likely to adhere to recommendations for subsequent treatment.<sup>21</sup> The literature describes various psychological barriers to obtaining follow-up care, including the fear that cancer will be found; a belief that Pap tests are needed only in cases of abnormal bleeding; and worries about examinations, treatments, or any impact on future fertility.<sup>7,21,22</sup>

■ **Figure 3.** Age-adjusted Incidence Rates of Invasive Cervical Cancer by Stage and Ethnicity



Source: Reference 22.

As previously mentioned, cervical cancer screening rates observed in different ethnic groups in the United States do not correspond well to their respective mortality rates. Most notably, black women undergo screening at a higher rate than any other ethnic group, yet they have the highest rate of death from cervical cancer. Examining the stage of invasive cancer at the time of diagnosis in the different ethnic groups may shed light on this subject. Black women are 1.9 times more likely to receive a diagnosis of distant invasive cervical cancer and 1.8 times more likely to receive a diagnosis of regional invasive cervical cancer compared with white women, but they are only 1.2 times more likely than white women to receive a diagnosis of localized invasive cervical cancer (Figure 3).<sup>23</sup> The relative survival rates for black women with cervical cancer are lower than the survival rate for white women and women overall, largely because their disease is diagnosed at a more advanced stage, which is associated with their lower socioeconomic status, on average.<sup>24,25</sup> Considering that black women undergo cervical screening at a higher rate than white women, the increased likelihood that their cancer will be diagnosed at a later stage suggests black women are less likely to receive appropriate follow-up care after an abnormal Pap test result. Recent literature reviews have examined the lack of follow-up observed in black and other ethnic populations and concluded that black women are less likely to receive treatment for cervical cancer or more likely to receive less intensive therapy.<sup>7</sup> It has also been determined that

black, Asian, and Hispanic women are less likely to comply with follow-up recommendations or receive follow-up care.<sup>18</sup>

Using Cox proportional hazards regression to compare populations with and without Medicaid insurance, the likelihood of finding late-stage disease was greatest for women who enrolled in Medicaid after receiving a diagnosis of cervical cancer.<sup>25</sup> Likewise, women younger than 65 years who enrolled in Medicaid after receiving a cervical cancer diagnosis were more likely to die from the disease than women who were not insured by Medicaid (hazard ratio, 2.4; 95% CI, 1.5-3.9).<sup>26</sup>

The relationship between socioeconomic factors and access to care appears to be highly relevant when considering ethnic disparities in cervical cancer care. Farley et al reviewed records for 1553 white and black women with invasive cervical carcinoma who were enrolled in the military healthcare system.<sup>27</sup> All the women had equal, direct access to primary care physicians and specialists, which was not hampered by cost, health insurance coverage, or racial barriers. In this racially and economically unbiased setting, no difference in the cervical cancer survival rate was observed between white and black women.<sup>27</sup> This emphasizes the impact that cultural disparities have on “real-world” healthcare practices and patient outcomes.<sup>27</sup>

### Primary Prevention

Prophylactic HPV vaccination is a preventive tool that needs to be considered when attempting to



decrease disparities among ethnic groups in invasive cervical cancer incidence. The HPV vaccine was recently introduced in managed care, and although it does not negate the need for screening, this primary prevention method might be of tremendous benefit to women whose cultural and socioeconomic barriers to secondary prevention cannot be overcome. Vaccination allows these women to avoid some of the cultural barriers associated with cervical screening, such as aversion to the invasiveness of the Pap test. Vaccination with the 3-dose injection schedule could also prove more attractive to economically disadvantaged populations.

Primary prevention via vaccination would potentially allow a proportion of cervical disease to be avoided altogether. This could compensate for some of the costs associated with abnormal Pap test results, such as repeat screening and colposcopy/biopsy and costs associated with treatment of cervical disease.

### Conclusion

Effective secondary prevention of cervical cancer, through screening and follow-up care, depends on several factors. At the center is the individual woman, who decides from the outset whether to adhere to recommendations for screening and treatment. Whether a woman undergoes regular screening and follow-up treatment is often influenced by her personal beliefs, cultural views, and socioeconomic status.

Cultural barriers to secondary prevention methods in minority populations result in correspondingly higher rates of morbidity and mortality due to cervical cancer, which has a significant impact on managed care. Minority populations also demonstrate less frequent adherence to recommendations for follow-up care, leading to poorer clinical outcomes and increased costs for managed care organizations.

Improving secondary prevention approaches may alleviate some of the cultural barriers to screening. For example, introducing multilingual screening programs could help overcome language barriers, and offering educational programs could increase women's adherence to regular screening recommendations. Future technological advances might reduce the costs, complications, and level of invasiveness associated with current screening

methods, but it is unclear whether these advances will ever be successfully implemented. In an attempt to overcome care-access issues related to a patient's income and financial status, government-funded interventions like the CDC's National Breast and Cervical Cancer Early Detection Program provide underserved women with access to screening services. These types of programs, however, do not address cultural barriers that inhibit a patient from obtaining follow-up care once an abnormality has been detected through screening.

Ultimately, a 2-tiered approach consisting of primary and secondary prevention of cervical cancer is needed to combat the disease effectively and reduce its economic burden on managed care. This approach is particularly important in managing care for women in ethnic subpopulations, where the current paradigm of secondary prevention has proved ineffective. The lack of improvement in secondary prevention methods makes this 2-tier approach even more important in attempting to overcome the disparity of care for women with cervical cancer among ethnic groups. Cervical cancer prevention efforts should focus primarily on providing access to primary prevention through HPV vaccination and directing educational messages about the need to undergo regular Pap test screening to those women who are at highest risk.

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**Funding Source:** Study supported by GlaxoSmithKline.

**Author Disclosures:** Consultant/Advisory Board/Speaker: GlaxoSmithKline (JSS).

**Author Information:** Concept and design, drafting of the manuscript, and critical revision of the manuscript for important intellectual content (JSS).

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