Symposium Issue: Cervical Cancer in South Carolina

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President’s Page

Never Give Up

There is nothing more on the minds of physicians, health care workers, and the general public than health system reform. It would be impossible for me to write about anything else for this month’s President’s Page. This point in history may be remembered as a time when the art, science, and business of medicine changed forever. Also, there are Constitutional issues as government proposals infringe on the freedom to make one’s own health decisions, thus taking away basic rights of the individual.

First, consider the financial situation of our country. The U.S. currently has over $106 trillion in unfunded obligations, or expected expenditures for past promises. Of this total, promised Medicare and Medicaid health care makes up $92 trillion, the remainder being Social Security obligations. As of September 30 of this year, we have a national debt of $12 trillion. The Congressional Budget Office projects another $9 trillion of debt over the next decade, so by 2019, we will have a debt of $21 trillion. Medicare is projected to go broke in 2017.

Current bills for health reform in the House and Senate will likely cost over $1 trillion during the next 10 years. The increased taxes required to fund this health package will not be used to reduce our debt or to meet the unfunded obligations listed above. Is this the right time to adopt a new, open-ended government entitlement that involves such a large percentage of our economy? I do not think so. Historically, federal government programs have not been known to be fiscally sound.

Any discussion of health system reform is difficult because the problems are multifaceted and complicated. And, most of us have different opinions about how to fix it. Our AMA Board has chosen to support H. 3962, recently passed in the House. This was a surprise to many physicians because much of this bill goes against AMA policy and common sense. At the recent AMA Interim meeting in Houston, the House of Delegates (HOD) passed Resolution 203 that addresses the AMA position on some of these issues. An important directive to our Board is to push medical liability reform to decrease the large expense of defensive medicine. The HOD calls for our Board to be more active and public in supporting reform alternatives that are consistent with known AMA policy. Thus far, the Board has been public in its support of the Democratic proposals in the House. However, they have not been public in telling its AMA members, Congress, or the public in general what the AMA supports or opposes in this debate.

I estimate that about 75-80% of physicians in South Carolina do not support the current Democratic proposals. This is not true in other areas of the country where there is more broad support for the bills. The Senate has been very secretive about the details of their reform plan, and this has created confusion and frustration among those interested in the details. The Senate process is also slower, once a bill is voted to be under debate. This allows those interested to see more deliberation and potential amendments. However, the Senate leadership is threatening to use a procedure that allows only a simple majority (51 votes) for passage rather than the more commonly used 60 votes to suspend debate (cloture) and vote.

Anyone’s guess is as good as mine about what might happen. We have to remain engaged. We should continue to educate our patients. We must stay in contact with our SC delegation in Washington. And, we must be true to our patients in protecting the patient-doctor relationship in the exam room and at the bedside, keeping insurers and government out of the process of actual patient treatment. Third party payers, both private and government, primarily focus on costs and give little attention to quality and access. We must not let cost be the main deciding factor about the care our patients receive.

Should we be worried? Consider this. Governments at the state and federal levels continue to discount physician services. This is a devaluation of our training and skills. It takes at least seven years to make a physician, often more. And, experience adds even more skills. There is little interest in Washington to restore private contracting between patients and physicians. Our House of Delegates directed the AMA Board to actively and publically support the inclusion in health services reform legislation of private contracting without penalty to the patient or physician. Will anyone listen?

We are pawns on an unpredictable roller coaster ride. But, remember: we are the only ones who can practice medicine and bring these skills to the care for patients. There is power in our standing together against others who are not involved in medicine and have little idea how to fix it. I ask that you never give up.

John G. Black, MD
President
talldoc2@aol.com
The Journal of the South Carolina Medical Association

The mission of The Journal is to advance the art and science of medicine; to promote the ideals of the South Carolina Medical Association; to encourage scholarship and good will among South Carolina physicians; and to disseminate information specifically applicable to the health care of South Carolinians.

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The Journal of the South Carolina Medical Association (ISSN 0038-3139) is published by the South Carolina Medical Association business office: 132 Westpark Blvd., Columbia, SC 29210.

Subscription price for the printed issue to non-members is $25.00. SCMA members’ subscription cost is $15.00 (included with payment of annual dues).

To advertise in the printed issue: Contact Kate Crosby, Managing Editor, journal@scmanet.org.

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Phone: (803) 798-6207
or (800) 327-1021
Website: www.scmanet.org
E-mail: journal@scmanet.org

Periodicals postage paid at Columbia, SC. POSTMASTER: Send address changes to The Journal of the South Carolina Medical Association, P. O. Box 11188, Columbia, SC 29211

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Cervical Cancer in South Carolina: Problems & Solutions Through Research, Practice, and Innovation

Heather Brandt, PhD; Saundra Glover, PhD, MBA

In the United States, in comparison to the rest of the world, rates of cervical cancer incidence and mortality are relatively low. However, problems persist that challenge us in our efforts to further decrease disease. The introduction of the Pap test in the mid-1900s and widespread participation in cervical cancer screening has been a tremendous breakthrough in cervical cancer prevention and control. Since that time, in the United States, we have seen a 75% reduction in deaths due to cervical cancer. The decline in deaths from cervical cancer in the United States, as well as the improved survival of women with advanced disease have resulted, according to experts, from widespread application of routine screening with the Pap test, the emergence of gynecologic oncology as a distinct medical subspecialty, and the completion of important clinical trials. Despite these advances, not all women have benefited equally. Women of color, women living in rural regions, and women with low income levels have seen fewer benefits in the United States and around the world and continue to develop and die of cervical cancer at much higher rates. Currently, South Carolina ranks fourteenth in cervical cancer incidence and mortality rates as compared to the rest of the United States.

The problem of excess cervical cancer disease is one for which potential solutions exist. First, we need to encourage and support women to have regular Pap tests as recommended by the American Cancer Society and other organizations putting forth evidence-based guidelines. Second, if a woman has an abnormal screening result, we need to encourage and support her in seeking follow-up care in a timely manner to make sure that the abnormalities do not progress to cervical cancer. Third, we must ensure that health care providers are aware of and practicing the latest screening, follow-up care, and treatment guidelines for cervical cancer. New tools and revised guidelines have improved cervical cancer prevention and control efforts, and health care providers and consumers need such information to most effectively screen for disease.

While cervical cancer screening has been effective in a larger sense, the identification of HPV as an etiologic factor in the development of cervical disease has resulted in the licensure, approval, and recommendation for the first vaccine for some types of HPV, called Gardasil® (Merck). Gardasil® is licensed for females aged 9 to 26 and recommended by the Centers for Disease Control and Prevention (CDC) for females aged 11 and 12 with catch up doses until age 26. Concerns about safety, the cost of the vaccine, and financing and delivery of the vaccine have resulted in mixed uptake, according to a recent study by the CDC (NIS-Teen). Recently, the United States FDA issued support for a second vaccine, Cervarix™ (GlaxoSmithKline), and for administration of Gardasil® to males. Additional efforts are needed to ensure that parents and individuals can make informed decisions related to HPV vaccination based on culturally- and literacy-appropriate, medically accurate information.

Even with new tools and old, some important social and behavioral factors remain paramount in our efforts to prevent cervical cancer so that disparities in cervical cancer are decreased rather than increased. The problem of cervical cancer is more complex when you consider the myriad factors and barriers related to getting a Pap test, getting follow-up care, and/or uptake of HPV vaccines. Awareness and knowledge of the connection between HPV and cervical cancer, transportation, increasing health care costs, taking time off work, and finding someone to care for children are examples of threats to further reductions in cervical cancer.

Cervical cancer is a disease that may only affect women in the physical sense, but all of us lose when a woman dies unnecessarily. The symposium focused on cervical cancer is designed to share with you a sample of the research, practice, and innovation being conducted by scientists, physicians, and members of the community. Unfortunately, only a few articles could be included in the symposium. We were unable to provide information on important local cervical cancer screening programs, such as the one operated by Palmetto Health in Columbia, research with sexual minority women, and studies of persistence and progression of HPV being conducted by researchers at the University of South Carolina. Further, we did not include studies focused on males, which has relevance due to the connection between HPV and other disease outcomes and the recent approval by the United States FDA to administer Gardasil® to males. We look forward to collaborating with anyone interested in addressing cervical cancer in South Carolina. We hope that you will join us in our efforts to address cervical cancer in South Carolina.
This publication is supported by Grant# 5P20MD001770-04, funded by the National Center on Minority Health and Health Disparities (NCMHD) at the National Institutes of Health (NIH). The content and views expressed in this publication are solely that of the author(s) and does not necessarily reflect the official views of the NIH.

Cover Design:
We sincerely thank Christina Johnson for designing the front cover of this Special Edition.

Dedication:
Some consider cervical cancer to be only a woman’s issue, and this may be true in the purely biological and physical sense. However, in South Carolina and around the world, cervical cancer is an issue that impacts not only women but families and communities. The cover art depicts the many faces of cervical cancer – women, men, children – in South Carolina. This issue is dedicated to all of the people whose lives have been affected by cervical cancer, to the clinicians, researchers, and public health practitioners invested in preventing and controlling cervical cancer, and to everyone who has an interest in moving to action with us to make a difference in South Carolina.

Answering the Call Acknowledgements:
A special thank you to Ms. Mary-Kathryn Craft, MA for her editorial assistance in the preparation of this community perspectives article.

“A Call to Action: Preventing Cervical Cancer among African-American Women” is supported by the South Carolina Cancer Disparities Community Network (SCCDCN) by Grant Number 1 U01 CA114601 from the National Cancer Institute as part of the Community Networks Program of the Center to Reduce Cancer Health Disparities of the National Institutes of Health and previously through a grant from the South Carolina Cancer Alliance.

The pilot project, “HPV Vaccine Acceptability and Promotion in Faith-Based Settings,” is supported by a supplement to the SCCDCN grant (1 U01 CA114601-03S4). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Pap and HIV Testing Behaviors Acknowledgements:
This research study was sponsored in part by an unrestricted educational grant from Gilead Science. The study findings reported in this manuscript are based on a secondary data analysis of the 2008 South Carolina Behavioral Risk Factor Surveillance System (SC BRFSS) survey data. The SC BRFSS survey is conducted by the South Carolina Department of Health and Environmental Control (SCDHEC) with funding and guidance provided by the Centers for Disease Control & Prevention (CDC), grant number 1U58DP001466.
Cervical Cancer in South Carolina: Epidemiologic Profile

Jonathan E. Savoy, MPH; Deborah M. Hurley, MSPH; Heather M. Brandt, PhD;
Susan W. Bolick-Aldrich, MSPH, CTR; Margaret E. Ehlers, MSPH

Note: Rates are per 100,000 and age-adjusted to the 2000 US Standard Population. Data years include 2002-2006. Rank is determined by lowest number being the worst and highest number being the best. Ranks only include state registries meeting NAACCR high quality data criteria.

Data Source: Data as of June 2009 reported by NAACCR as meeting high quality standards for 2002-2006 and include data from state and provincial cancer registries participating in SEER, NPCR, or both, in the U.S. and the Canadian Cancer Registry in Canada and underlying United States mortality data provided by NCIS (www.cdc.gov/nchs). ACS 2009 Supplemental Data.

### Table 4: Stage of Cervical Cancer at Diagnosis by Race (2002-2006)

<table>
<thead>
<tr>
<th>Race</th>
<th>Local</th>
<th>Regional</th>
<th>Distant</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, All Races</td>
<td>51.4%</td>
<td>32.7%</td>
<td>6.9%</td>
<td>9.1%</td>
</tr>
<tr>
<td>Black Female</td>
<td>45.9%</td>
<td>35.6%</td>
<td>8.7%</td>
<td>9.8%</td>
</tr>
<tr>
<td>White Female</td>
<td>54.6%</td>
<td>31.4%</td>
<td>6.1%</td>
<td>8.0%</td>
</tr>
</tbody>
</table>

Note: All races include White, Black, and Other.

Source: South Carolina Central Cancer Registry

### Table 5: Female Age Distribution in South Carolina

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Population (n)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;18</td>
<td>520,555</td>
<td>22.6%</td>
</tr>
<tr>
<td>18-24</td>
<td>211,191</td>
<td>9.2%</td>
</tr>
<tr>
<td>25-44</td>
<td>601,601</td>
<td>26.2%</td>
</tr>
<tr>
<td>45-64</td>
<td>620,323</td>
<td>27.0%</td>
</tr>
<tr>
<td>65+</td>
<td>344,852</td>
<td>15.0%</td>
</tr>
</tbody>
</table>

Data Sources: Population Division, U.S. Census Bureau, Annual Estimates of the Resident Population by Sex and Age for South Carolina: April 1, 2000 to July 1, 2008 (SC-EST2008-02-45).

### Table 6: State Level Data, 2009 Estimates

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000 Census Population (State)</td>
<td>4,012,012</td>
</tr>
<tr>
<td>2000 Census Population (Females)</td>
<td>2,063,083</td>
</tr>
<tr>
<td>2008 Estimate (Females) ¹</td>
<td>2,298,522</td>
</tr>
<tr>
<td>White, Non-Hispanic</td>
<td>1,489,824</td>
</tr>
<tr>
<td>Black, Non-Hispanic</td>
<td>668,686</td>
</tr>
<tr>
<td>Native American, Non-Hispanic</td>
<td>7,972</td>
</tr>
<tr>
<td>Asian/Pacific Islander, Non-Hispanic</td>
<td>28,626</td>
</tr>
<tr>
<td>Hispanic</td>
<td>80,829</td>
</tr>
<tr>
<td>Other/Multi-Race, Non-Hispanic</td>
<td>22,585</td>
</tr>
</tbody>
</table>

¹Total is sum of White, Black, Native American, Asian/Pacific Islander, Other/Multi-Race and Hispanic Data Sources: Population Division, U.S. Census Bureau, ACS South Atlantic Division Cancer Facts & Figures 2009
Table 7: Cervical Cancer 5 year Observed Survival Rates by Grade and Race (2001-2005)

Table 8: Cervical Cancer 5 year Observed Survival Rates by Stage and Race (2001-2005)

Note: Excludes in situ cancers and children (ages 0-19). Cervical Uteri Cancer 5-yr Observed Survival Rate (%) by SEER Stage at Diagnosis and Race, South Carolina, 1996-2005. Cervical Uteri Cancer 5-yr Observed Survival Rate (%) by Grade at Diagnosis and Race, South Carolina, 1996-2005.
Sources: South Carolina Central Cancer Registry.

Table 9: 2002-2006 Ranking of Cervical Cancer Incidence and Mortality by State

Note: Ranks only include state registries meeting NAACCR high quality data criteria.
Sources: Data as of June 2009 reported by NAACCR as meeting high quality standards for 2002-2006 and include data from state and provincial cancer registries participating in SEER, NPCR, or both, in the US and the Canadian Cancer Registry in Canada. To account for population anomalies caused by Hurricane Katrina in 2005, statistics exclude data for AL, LA, and TX from July 2005 through December 2005.
Cervical Cancer Trends in South Carolina

Table 10: Incidence Trend: U.S. and South Carolina (1996-2006)

Table 11: Mortality Trend: U.S. and South Carolina (1996-2006)

Note: Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population.
Source: South Carolina Central Cancer Registry, SEER Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 6.5.2
Cervical Cancer Prevention and Control

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual survey administered by the Centers for Disease Control and Prevention (CDC). The following map and chart are based on 2008 data in response to a question asked of women, aged 18 and older, regarding having a Pap test in the past three years.

Table 13: 2008 BRFSS Survey Map: Data for Pap Test within the Past Three Years

Legend

<table>
<thead>
<tr>
<th>Percent</th>
<th>≤ 79.8</th>
<th>79.9 to 81.7</th>
<th>81.8 to 83.3</th>
<th>83.4 to 84.5</th>
<th>≥ 84.6</th>
<th>No Data</th>
</tr>
</thead>
</table>

Table 14: 2008 BRFSS Survey Data: US and SC Percentages by Demographic, Race, and Age

<table>
<thead>
<tr>
<th>HOUSEHOLD INCOME</th>
<th>South Carolina</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $15,000</td>
<td>75.2</td>
<td>71.7</td>
</tr>
<tr>
<td>$15,000-$24,999</td>
<td>82.6</td>
<td>76.3</td>
</tr>
<tr>
<td>$25,000-$34,999</td>
<td>89.6</td>
<td>81.3</td>
</tr>
<tr>
<td>$35,000-$49,999</td>
<td>90.0</td>
<td>84.4</td>
</tr>
<tr>
<td>$50,000+</td>
<td>92.2</td>
<td>90.6</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>EDUCATION</th>
<th>South Carolina</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less Than High School</td>
<td>69.6</td>
<td>73.6</td>
</tr>
<tr>
<td>High School or G.E.D.</td>
<td>80.6</td>
<td>76.9</td>
</tr>
<tr>
<td>Some Post-High School</td>
<td>88.3</td>
<td>82.9</td>
</tr>
<tr>
<td>College Graduate</td>
<td>93.8</td>
<td>90.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RACE</th>
<th>South Carolina</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>84.5</td>
<td>82.9</td>
</tr>
<tr>
<td>Black</td>
<td>90.4</td>
<td>86.2</td>
</tr>
<tr>
<td>Other</td>
<td>90.5</td>
<td>81.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HISPANIC</th>
<th>South Carolina</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>88.9</td>
<td>85.2</td>
</tr>
<tr>
<td>No</td>
<td>11.1</td>
<td>14.8</td>
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<table>
<thead>
<tr>
<th>AGE</th>
<th>South Carolina</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>72.0</td>
<td>73.8</td>
</tr>
<tr>
<td>25-34</td>
<td>93.2</td>
<td>91.3</td>
</tr>
<tr>
<td>35-44</td>
<td>89.9</td>
<td>89.3</td>
</tr>
<tr>
<td>45-54</td>
<td>89.1</td>
<td>86.2</td>
</tr>
<tr>
<td>55-64</td>
<td>82.7</td>
<td>84.3</td>
</tr>
<tr>
<td>65+</td>
<td>76.9</td>
<td>65.8</td>
</tr>
</tbody>
</table>

Data Sources: Behavioral Risk Factor Surveillance System Survey (BRFSS) Survey Results 2008 for South Carolina & the United States

The University of South Carolina/Clai5lin University Center of Excellence (COE) in Cancer and HIV Research is funded by the National Institutes of Health’s (NIH) National Center for Minority Health and Health Disparities (NCMHD). Led by Dr. Saundra Glover, Director of the USC Institute for Partnerships to Eliminate Health Disparities, Dr. Kim Creek, Professor, USC School of Medicine, and Dr. Rebecca Bullard-Dillard, Biology Professor and Assistant Vice-President for Academic Affairs at Clai5lin University, the COE team recognizes and is dedicated to taking knowledge gained from research and delivering solutions that lead to improved health status and health equity for communities, populations, and individuals. The Center emphasizes community partnerships and involvement in research, education, training, and outreach as essential to fostering a healthier community and state.

As such, the COE team is dedicated to addressing health disparities, particularly those related to cervical cancer. Center efforts could not have been realized without help from a variety of partners from around South Carolina, to include health care providers, public health professionals, and community organizations engaged in biomedical and behavioral research, prevention, and intervention activities designed to educate minority populations about health disparities. Among them is the James E. Clyburn Health Disparities Health Disparities Lecture Series that began in April 2008. Now an annual event, the lecture series brings together researchers and public health professionals in an interactive forum to discuss ways to address and eliminate health disparities that continue to plague communities in South Carolina and across the United States.

Over the years, a variety of educational activities have occurred that have promoted the participation of health disparities groups in biomedical and behavioral research, prevention, and intervention activities designed to educate minority populations about health disparities. Among them is the James E. Clyburn Health Disparities Health Disparities Lecture Series that began in April 2008. Now an annual event, the lecture series brings together researchers and public health professionals in an interactive forum to discuss ways to address and eliminate health disparities that continue to plague communities in South Carolina and across the United States.

As a result of the Clyburn Health Disparities lecture and building upon concurrent efforts to address cervical cancer in South Carolina, Moving to Action (MTA), an initiative to address Cervical Cancer in South Carolina evolved in June 2008. The Center of Excellence (COE) staff enlisted support from representatives from the South Carolina Cancer Disparities Network (SCCDCN) and the South Carolina Cancer Alliance (SCCA) to assist with convening a planning group of researchers, public health professionals and other stakeholders including members of the community to discuss ways to address cervical cancer disparities in South Carolina. A concerted effort was made to ensure the participation of coordinators of state comprehensive cancer control programs, representatives of government agencies, members of service provider organizations, and advocates. This team’s work lead to a two-day summit, in June 2008, in Columbia, SC which provided a venue for diverse stakeholders and participants to come together to discuss cervical cancer and to stimulate conversations that would lead to the development and implementation of strategies to address these disparities through education, social, and policy changes.

More than fifty stakeholders from across the state of South Carolina attended the Summit, which allowed a broad group of state and local leaders to share ideas. Discussions focused on education, policy change, and opportunities to address cervical cancer. Ensuring equal access to cervical cancer screening, promoting and supporting adherence to follow-up care of abnormal screening results, and understanding issues related to HPV vaccination were identified as ideal opportunities for continued work. Strategies included partnering with existing entities engaged in efforts to address cervical cancer as well as introducing and supporting policy change to maintain the expansion of the state cervical cancer screening program (The Best Chance Network) and proposing new policies to address gaps in funding for follow-up care of abnormal screening results. In addition, education was needed not only for the public, in general, but also for policymakers and even clinicians due to the rapidly changing standards in cervical cancer prevention and control. Reports of priorities and strategies developed at the summit were circulated to all participants and to all other interested stakeholders.

The Moving to Action Summit launched the effort that has continued as the “Cervical Cancer Subcommittee” of the South Carolina Cancer Alliance (SCCA). The subcommittee is part of the Breast and Female Work Group and Early Detection
Task Force within the SCCA, and the work of the subcommittee is being completed by three teams: Public Education and Communication, Health Care Provider Education, and Policy and Access to Care.

In January 2009, a statewide billboard campaign was launched to increase awareness of HPV and cervical cancer. The billboard campaign was supported with funds from the American Cancer Society, South Carolina Cancer Alliance, Palmetto Health, and the South Carolina Advertising Association. Billboards featured messages to “Stop Cervical Cancer” and included action-oriented steps such as being screened regularly for cervical cancer, following up on abnormal screening results, and learning more about the HPV vaccine.

This special issue of the Journal of the South Carolina Medical Association is another follow up activity of the Moving to Action effort. Other efforts have included developing a process to deliver educational updates and materials on cervical cancer to health care providers, in addition to communicating with legislators. This was done in an attempt to advocate for funding to provide cancer care to women diagnosed in our state, but who are unable to afford treatment.

While not insurmountable, there are a myriad of challenges that remain. The continued success of cervical cancer prevention and control efforts will require a strong, focused and sustained campaign, along with continued positive dialogue among all stakeholders at the local and national level. Now more than ever, strong and effective partnerships will be critical to facilitating movement and action, and the organizers and participants of MTA remain committed to building upon the work described in this Special Edition.
Despite multiple national health initiatives aimed at prevention, over 11,000 new cases of cervical cancer were expected to be diagnosed in the United States in 2008, and nearly 4,000 deaths are attributed to cervical cancer annually.¹ Significant disparities exist in incidence rates of cervical cancer along lines of ethnicity, race, geography, and socioeconomic status. These disparities are evident in South Carolina where rates of cervical cancer among African American and Hispanic women are several folds higher than their European American counterparts.²-⁴ Even with the adjustment of multiple risk factors, race/ethnicity continues to be an independent risk factor for higher morbidity and mortality from cervical cancer in South Carolina.²-⁵

Disparities in cervical cancer incidence and mortality by race exist and persist. African American women have higher incidence and mortality rates of cervical cancer. Such disparities raise the question of other co-factors or medical conditions that may contribute to progression of disease or poorer outcomes in cancer survival. There is certainly a need for more research as suggested by authors in this journal regarding investigations into other co-factors, such as BMI, smoking, and diabetes, and their association with progression to high grade cervical disease and cervical cancer. These are common health problems in low-income and minority communities and have been shown to increase risk of other types of cancer, such as breast and lung.

Frequently, these high-risk populations do not have adequate access to preventive care options, or they may have access but, for various reasons, choose not to utilize available services. Poor adherence to post-screening follow-up healthcare visits and disparate approaches to management of abnormalities found through screening can also impact survival in low-income populations. In the US and across the globe, cervical cancer incidence is a marker of poverty. A disproportionate number of poor minority women have higher rates of morbidity and mortality from cervical cancer.⁶ In areas where >20% of residents live under the poverty line, cancer incidence is greater than in areas with <10% of residents are living under the poverty line.⁷ Women living below the poverty line are three times more likely to be infected with a high-risk strain of HPV in the US compared to those who are not poor.⁸ South Carolina has one of the highest rates of uninsured women, and the numbers are dramatically worse for low-income women in the state.⁹ Clearly the differences in incidence and mortality that exists with cervical cancer, a disease potentially preventable and treatable, reveals the gaps in healthcare delivery and the need for aggressive public health initiatives.

Un fortunately some healthcare providers assume that nonadherence to follow-up of abnormal Pap tests or to healthcare providers’ recommendations are due to fear, distrust, or lack of interest by the patient in their healthcare. In reality as suggested by these papers, the process by which women from these populations address a diagnosis of HPV and cervical cancer is complex. Initially, it may involve fear or distrust, but not a lack of interest in their healthcare. Rather, it is an active and deliberate process of seeking and receiving support and planning, and coordinating their next steps. As reported by one article “low-income African American women had actively engaged in complex cognitive, behavioral, and social processes in making follow-up happen.” These findings, and all those presented in this journal from a scientific and community perspective, should inspire the healthcare system to discover innovative strategies to facilitate follow-up in these challenging communities and communication between patients and providers to improve care. Culturally appropriate and medically accurate education with emphasis on risk reduction, prevention and screening should not be understated. Too many misconceptions or myths exist surrounding the patients’ understanding of HPV and cervical cancer and the intentions of the healthcare system with regards to the HPV vaccine.¹⁰⁻¹¹ Community-based partnerships will be an important part and a needed investment in addressing these misconceptions and in reducing health disparities.

As such the importance of this cervical cancer journal issue which presents not only the science but the community perspectives, reflecting the need for prevention, collaboration, and certainly community-based and/or translational research if we are going to put a dent in disparities in cervical cancer. It is through the untiring efforts of the dedicated faculty and staff of the Institute for Partnerships to Eliminate Health Disparities (IPEHD) under Dr. Saundra Glover’s leadership that an aggressive agenda to eliminate these disparities through research, education and community engagement has become a priority. The hard work of Dr. Heather Brandt and her team of interdisciplinary researchers in partnership with IPEHD and its community partners have articulated a focused and targeted
mission to prevent and control cervical cancer in South Carolina. Policymakers should review these strategies and use the information presented in this journal as a foundation for addressing cervical cancer health disparities in South Carolina. Clearly, South Carolina will need to take deliberate and aggressive measures to reduce the disparity which exists for cervical cancer among minorities and the poor. Investing in healthcare and public health strategies that focus on preventing cervical cancer will reduce morbidity and mortality from this disease and its cost on society.

References
“We learn from our own cultural and ethnic backgrounds how to be healthy, how to recognize illness, and how to be ill... meanings attached to the notions of health and illness are related to basic, culture-bound values by which we define a given experience and perceptions.” — Rachel E. Spector, 1985

Historically the community has always been a strong key to social change. Whether it has been to acquire the right to vote, the right to be educated, or the right to influence health care, health education and health promotion, research supports the community effecting change. As Chavis (1990) so rightly put it, “When people share a strong sense of community they are motivated and empowered to change the problems they face, and are better able to mediate the negative effects over things which they have no control.” Simply stated, when the community residents, community-based organizations, and institutions that will be affected are involved in initiating and promoting it, permanent successful change is more likely to occur.

While communities and the definitions of community vary, within the past few years, some of South Carolina’s communities, individuals and community-based organizations have been at the forefront...setting the stage for change at the local and state levels as it relates to Cervical Cancer awareness, education and screening. Various processes, community-based participatory approaches and community engagement principles have been utilized to involve the community statewide.

A key principle for involvement, as exemplified by the authors of articles in this journal and their respective partners and collaborators, requires going to the community, establishing a relationship, building trust, working with formal and informal leadership, and seeking commitments from community organizations and leaders to create the process to mobilize the community. The community section of this special edition of the Journal of SCMA highlight some of the ways in which the aforementioned strategies have been implemented to address cervical cancer in SC, which include:

- Personal testimonies and beliefs being shared with a Center of Excellence, and Historically Black Colleges and Universities personnel.
- An African-American faith-based organization and its leadership committed and working with research faculty utilizing the 9 key elements of community-based participatory research approaches.
- Informal leadership within the Hispanic community accepting the challenge to educate and advocate from a local Hispanic/Latino Health Coalition.
- The Center of Excellence (COE) for HIV and Cancer Research, a partnership between the University of South Carolina and Claflin University, is designed to reduce health disparities in HIV/AIDS and HPV/cervical cancer, particularly among minorities in rural areas of South Carolina. The partnership is a result of a federally funded grant from the National Institutes of Health’s (NIH) National Center on Minority Health and Health Disparities (NCMHHD).
- The COE has been instrumental in addressing Cervical Cancer and Human Papillomavirus (HPV) in Orangeburg County. It works to assist with research activities and to design community-led programs and resources to educate and promote awareness about these health conditions.
- The University of South Carolina Cancer Disparities Community Network (SCCDCN) is a partnership between the State Baptist Young Woman’s Auxiliary of the Woman’s Baptist Education and Missionary Convention of SC, the South Carolina Primary Health Care Association, and the Carolina Community Based Health Supports Networks. The SCCDCN is one of 25 National Cancer Institute funded Cancer Network Programs of the Center to Reduce Cancer Health Disparities.

As you read the community articles, look to see how the heart...
and soul of the community has been placed at the center to make a difference in the lives of their respective communities and congregations, as well as how the authors shaped their overall efforts to ensure the community’s success. Look also to see how collaborations and partnerships were keys to success, as well as how there might be new opportunities to shape future initiatives. In moving forward, please continue to support these efforts and as Vena (2006) so eloquently states, “working together, we can make cancer prevention in South Carolina a reality.”

Acknowledgements
We gratefully acknowledge Dr. Sharon Bond, Mr. Richard Demarest and other external reviewers for their editorial assistance in the preparation of the community perspectives for this special edition of the Journal of the SC Medical Association.

References
Racial Disparities in Cervical Cancer Mortality in an African American and European American Cohort in South Carolina

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Introduction
In 2008, the American Cancer Society estimates that approximately 11,070 new cases of invasive cervical cancer were diagnosed with 3,870 subsequent cervical cancer deaths.1 South Carolina (SC) has some of the largest health disparities in the nation, in particular cancer mortality rates that disfavor African Americans (AA) in comparison to European Americans (EA).2 Using electronic data sources, the age-adjusted incidence rate of cervical cancer in SC from 1996 to 2005 was 37% higher for AA women compared to EA women (8.9/100,000 for EA, and 14.1/100,000 for AA).3 These same electronic data sources indicate that age-adjusted mortality is 61% higher in AA than EA women (2.4/100,000 for EA, and 3.9/100,000 for AA).3 Cervical cancer is one of the few cancers for which screening represents a primary prevention tool (i.e. lesions can be detected in precursor stages), thus the majority of all cases and ultimately deaths may be prevented by appropriate screening. AA women living in rural SC are among the least likely population to have received recommended screenings.4

Mortality disparities in cervical cancer have been partially explained by the lack of early detection due to non-adherence to screening protocols, but the racial disparity gap between EA and AA cannot be explained entirely by differences in screening rates.4 An analysis of Surveillance, Epidemiology, and End Results (SEER) Program data from 1988 to 1994, found 43.8% of AA women and 34.8% of EA women were diagnosed with advanced disease.5 With adjustment made for other factors, race was still found to be a significant predictor of cervical cancer.6 AA were also found to be at a 19% increased risk of death compared to EA over a five-year follow-up period after adjusting for several factors such as age at diagnosis, histology, stage, and first course of cancer-directed therapy.2 The independent effects of race and socioeconomic status have been intensely studied in the cervical cancer mortality literature.7-19 While many have concluded that race has an effect on cervical cancer survival independent of socioeconomic status, others have found that all disparities were explained by socioeconomic status alone.4, 13, 17 Howell and colleagues concluded that more work was needed to determine the basis of the racial disparity.5

Interestingly, further research analyzing SEER data using census tracts to establish “Working Poor” and “Professional” regions found that race was not as strong of a predictor as was access to care.20 Another similar study found that stage of disease and treatment type were more influential than race and socioeconomic status on mortality.5 With this mounting evidence on the possible sources of the mortality disparity between EA and AA populations, other factors such as comorbidity, severity of disease at diagnosis, and socioeconomic status should be considered both individually and in combination with each other.5

The lack of consensus on the causes of disparities in cervical cancer mortality highlights the need to better understand differences in clinical disease between EA and AA. In addition, very few studies have attempted to describe the disparities among rural AA and EA women. As SC is a predominately rural state with AA representation of over 30%,22, it offers the ideal population in which to further expand our knowledge of cervical cancer disparities. Fortunately, as a cancer for which screening represents a primary prevention tool, interventions within those populations at risk have the immediate potential to significantly impact these racial disparities. In order to fully understand the extent of these disparities, the purpose of this investigation was to determine whether AA women with cervical cancer were more likely to die than EA women with cervical cancer.

Methods
All data utilized for this analysis were collected as part of the SC Central
The state registry maintains a “gold certification” rating through the North American Association of Central Cancer Registries (NAACCR). Consequently, the data are of high quality, validity, and completeness. Due to the fact that all data for this analysis had been previously collected for reporting purposes and were de-identified, the investigation was exempt from Institutional Review Board review.

**Study Population**

The study population consisted of all women diagnosed with a histopathologically confirmed, first primary cervical neoplasm within SC between January 1, 1996 and December 31, 2006. The registry used ICD-O-2 and ICD-O-3 codes depending on the year of diagnosis (C53.0-C53.9) in combination with histology to exclude any non-cervical neoplasms. Women were excluded if they had a previous cancer diagnosis or were under 20 years of age. They also were excluded if the cervical cancer diagnosis was documented only upon autopsy or the death certificate. It should be noted that specific cause of death is a restricted data element for the SCCCR and was not available for analysis. Only those women with a race designation of either “Black” or “White” (designations used by the registry) were used for this investigation. As the registry categorizes all other ethnicities into an “other” category, we were unable to extend this analyses beyond these racial groups. A total of 2,027 women were identified who met the inclusion criteria.

### Variables

Histology, defined by ICD-O-324, was collapsed into 5 groups using the first 3 digits of the classification, general neoplasm (800), general carcinoma (801), squamous cell carcinoma (807), adenocarcinoma (814, 838, or 856), and all others. Marital status was categorized as single; separated, including divorced, or widowed; married; or unknown. Information on cancer treatment was not routinely collected by the registry until 2006 and was missing for more than 75% of cases in this cohort. Additional variables under study included alcohol use (never, current, past, or unknown), age at diagnosis, grade (well differentiated, moderately differentiated, poorly differentiated, undifferentiated, and unknown), stage (local, regional, distant, un-staged), cause of death (cancer, other, unknown), year of diagnosis, and year of death.

### Statistical Analysis

An alpha level of 0.05 was used to determine statistical significance for all tests. Analyses were conducted using SAS version 9.2 (Cary, NC). Descriptive statistics were calculated and compared by race using either a Chi-square test or t-test, as appropriate. The data are comprised of a linkage (using both SAS and Link Plus software) between 1996-2005 SC cervical cancer incidence data linked to 1996-2006 SC death certificate data and 1996-2006 National Death Index.
(NDI) data\textsuperscript{26} and 1996-2006 Social Security Death Index (SSDI) data\textsuperscript{27} using a combination of both deterministic and probabilistic matching. All SCCCR data not matched through the vital records linkage are prepared and sent to NCHS for linkage to the NDI. Results provided are run through a National Program of Cancer Registries approved algorithm to determine true, probable, and non-matches. True matches are accepted, probable matches are manually reviewed, and non-matches are considered to be alive (total match rate=48.1%). After linkage, cases not found to be deceased as of December 31, 2006, were considered to be alive at the time of censoring. Survival time for each woman was calculated as the number of days between the date of diagnosis and either the date of last follow-up (December 31, 2006; for all those categorized as “alive”) or date of death (for those categorized as “deceased”), or date of secondary malignancy. For those with a secondary malignancy, they were classified as “alive” for survival analyses and censored at the date of diagnosis for the second malignancy. Kaplan Meier survival curves were calculated and the log rank test statistic was used to assess for statistical differences between racial groups. In order to evaluate racial differences by tumor type, curves were calculated within specific sub-groups using the \textit{WHERE} function.

**Results**

The characteristics of the population are shown in Table 1. Significant differences between races were noted for alcohol use, grade, histology, marital status, and vital status. Of note, over 30% of the data for alcohol use was unknown (missing). The proportion of deceased women was significantly higher among AA women compared to EA women (44% vs 29%, \(p < 0.01\)). For both racial groups, squamous cell carcinoma and adenocarcinoma were the most common histologies noted at diagnosis; however, a larger proportion of AA women were diagnosed with squamous cell cancers. For both grade and stage, AA women were significantly more likely than EA women to be diagnosed with poorer-prognosis tumor types.

Table 2 describes the 3-, 5-, and 10-year survival proportions for AA and EA women by different cervical cancer sub-populations. Significant racial differences in survival were observed in the entire population with a 10-year survival proportion of 49% for AA and 66% for EA women (\(p < 0.01\)). This is also illustrated graphically in Figure 1. Upon stratification by stage, AA women with local or regional disease had significantly lower survival at 10 years than EA women (69% vs 81% and 30% vs 43%, respectively). Similarly, significantly lower survival was found for AA

### Table 1. cont’d.

<table>
<thead>
<tr>
<th>Variable</th>
<th>AA % (n)</th>
<th>EA % (n)</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vital Statistics</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Status:</td>
<td></td>
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<tr>
<td>Alive</td>
<td>56 (415)</td>
<td>71 (877)</td>
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<tr>
<td>Dead</td>
<td>44 (331)</td>
<td>29 (351)</td>
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<tr>
<td>Cause of Death:</td>
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<tr>
<td>Cancer</td>
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<td>75 (265)</td>
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<tr>
<td>Other</td>
<td>19 (62)</td>
<td>19 (66)</td>
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<tr>
<td>Unknown</td>
<td>5 (17)</td>
<td>6 (20)</td>
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</tr>
<tr>
<td>Year of Death:</td>
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<td>2005</td>
<td>7 (54)</td>
<td>8 (98)</td>
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</table>

\(\text{EA} – \text{European American; AA- African American}
\)

*From Chi-square test for homogeneity

EA – European American; AA- African American

---

*From Chi-square test for homogeneity
### Table 2. Kaplan Meier survival results for African American and European American cervical cancer patients, 1996-2006.

<table>
<thead>
<tr>
<th>Population</th>
<th>Ethnicity</th>
<th>N</th>
<th>3-Year Survival</th>
<th>5-Year Survival</th>
<th>10-Year Survival</th>
<th>p-value*</th>
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<tr>
<td>Overall</td>
<td>AA</td>
<td>746</td>
<td>62%</td>
<td>55%</td>
<td>49%</td>
<td>&lt;0.01</td>
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<tr>
<td></td>
<td>EA</td>
<td>1228</td>
<td>76%</td>
<td>72%</td>
<td>66%</td>
<td></td>
</tr>
<tr>
<td>Stage:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local Stage</td>
<td>AA</td>
<td>387</td>
<td>81%</td>
<td>75%</td>
<td>69%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>EA</td>
<td>762</td>
<td>90%</td>
<td>86%</td>
<td>81%</td>
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<tr>
<td>Regional Stage</td>
<td>AA</td>
<td>235</td>
<td>47%</td>
<td>40%</td>
<td>30%</td>
<td>&lt;0.01</td>
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<tr>
<td></td>
<td>EA</td>
<td>313</td>
<td>59%</td>
<td>52%</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td>Distant Stage</td>
<td>AA</td>
<td>71</td>
<td>11%</td>
<td>10%</td>
<td>10%</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>EA</td>
<td>73</td>
<td>18%</td>
<td>18%</td>
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<td>AA</td>
<td>10</td>
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<tr>
<td></td>
<td>EA</td>
<td>21</td>
<td>75%</td>
<td>70%</td>
<td>57%</td>
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<tr>
<td>General Carcinomas</td>
<td>AA</td>
<td>25</td>
<td>41%</td>
<td>36%</td>
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<tr>
<td></td>
<td>EA</td>
<td>39</td>
<td>71%</td>
<td>65%</td>
<td>44%</td>
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</tr>
<tr>
<td>Squamous Cell</td>
<td>AA</td>
<td>593</td>
<td>67%</td>
<td>63%</td>
<td>54%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>EA</td>
<td>862</td>
<td>76%</td>
<td>71%</td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Adenocarcinomas</td>
<td>AA</td>
<td>76</td>
<td>46%</td>
<td>35%</td>
<td>35%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>EA</td>
<td>232</td>
<td>81%</td>
<td>79%</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>All Other Histology</td>
<td>AA</td>
<td>42</td>
<td>29%</td>
<td>22%</td>
<td>22%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>EA</td>
<td>74</td>
<td>69%</td>
<td>67%</td>
<td>67%</td>
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<td>Grade:</td>
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<td></td>
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<tr>
<td>Well Differentiated</td>
<td>AA</td>
<td>42</td>
<td>84%</td>
<td>80%</td>
<td>80%</td>
<td>0.87</td>
</tr>
<tr>
<td></td>
<td>EA</td>
<td>113</td>
<td>85%</td>
<td>83%</td>
<td>80%</td>
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<tr>
<td>Moderately Differentiated</td>
<td>AA</td>
<td>188</td>
<td>69%</td>
<td>61%</td>
<td>57%</td>
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<td>Poorly Differentiated</td>
<td>EA</td>
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<tr>
<td>Undifferentiated</td>
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<td>28</td>
<td>68%</td>
<td>63%</td>
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<td></td>
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<td>Single</td>
<td>AA</td>
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<td>64%</td>
<td>60%</td>
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<td>54%</td>
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<td>640</td>
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<td>77%</td>
<td>72%</td>
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<td>Divorced, Widowed,</td>
<td>AA</td>
<td>245</td>
<td>51%</td>
<td>45%</td>
<td>37%</td>
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<td>Separated</td>
<td>EA</td>
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<td>68%</td>
<td>63%</td>
<td>54%</td>
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<td>50%</td>
<td>46%</td>
<td>40%</td>
<td>&lt;0.01</td>
</tr>
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<td></td>
<td>EA</td>
<td>104</td>
<td>64%</td>
<td>59%</td>
<td>57%</td>
<td></td>
</tr>
</tbody>
</table>

EA – European American; AA- African American  
*From log rank test for Kaplan Meier survival curves
Racial Disparities in Cervical Cancer Mortality in an African American and European American Cohort in South Carolina

In examining differences by grade, AA women diagnosed with moderately and poorly differentiated tumors experienced significantly lower survival at 10 years than EA women (57% versus 66% and 40% versus 57%, respectively). In order to examine how social support networks might influence survival, we examined survival by marital status (as a rough estimator). Significantly lower survival was found for AA women in the married and divorced/widowed/separated groups (all p-values < 0.01).

Discussion
With this investigation, we found significantly decreased survival among AA women with cervical cancer compared to EA women. The disparity persisted even among AA and EA women with the same disease stage, grade, or histology. These findings help to highlight the extent of the disproportionate burden of cervical cancer disease that AA women experience. This work also extends our understanding of the disparities among rural AA women who comprise much of this population.

The causes of these disparities are most likely multi-faceted and interdependent. On one end of the spectrum, these disparities may be partly attributable to natural variation in biological processes and functioning reflecting genetic and environmental factors and the interactions between them. On the other end of the spectrum, these disparities could be influenced by socioeconomic factors such as access to appropriate screening and post-diagnosis care. Still other possible factors influencing survival may be related to environmental and provider barriers to receiving appropriate cervical cancer screening and care.

With our analysis of the impact of marital status on mortality, we attempted to account for possible social support. While marital status is an extremely crude measure of support, it is interesting that AA women in all four categories experienced significantly poorer survival. As would be expected, the highest survival proportions were noted in the married group, which is consistent with other studies showing a positive influence of social support on health outcome.

Women may also receive other forms of support (family, friends, or church) which we were not able to account for by using marital status. While these findings certainly point out a need for further research, they also suggest areas for possible intervention. Marital status may be an indicator of emotional or psychological support, financial support, or support in “care-taking” responsibilities. Programs aimed at providing this type of support for AA women may also be necessary to improve their survival outcomes.
support could have a significant impact on cervical cancer survival.

An important milestone in the history of cervical cancer is the development of a human papillomavirus (HPV) vaccine. As the majority of cervical cancer cases are preceded by HPV infection, administration of the vaccine has tremendous potential to prevent the development of cervical cancer. As the numbers of individuals who choose to be vaccinated increase, it will be important to understand the effect of vaccine use on cervical cancer survival.

The Cancer Plan for SC is a document which seeks to formulate and organize a cohesive strategy for addressing cancer prevention and control in SC. The plan specifically highlights possible strategies to eliminate health disparities in cancer. Consequently, this investigation addresses several key areas of the plan such as increasing awareness of racial disparities, aid in the dissemination of information about disparities, and educate key legislative officials about disparities. We see this work as an important first step which highlights the need for additional research to further understand the disparities and develop or disseminate interventions aimed at addressing the determinants of the disparities.

Several limitations should be considered when interpreting the findings from this study. While the SC Central Cancer Registry contains a wealth of data, information on the treatment course was not available for analysis. Given that post-diagnosis care is an important factor for survival, we were not able to evaluate disparities in cervical cancer treatment. It should also be noted that marital status information, while collected by the SCCCR, is not a required data element and is not quality controlled. Additionally, due to a large proportion of missing data, we were not able to account for the potential effect of socioeconomic indicators such as insurance type or education. On a similar note, we had no information on screening behaviors, which have been found to significantly impact cervical cancer mortality. While none of these factors impact the internal validity of the analysis, they do have implications for generalizability of the findings.

On the other hand, this investigation has many strengths. Because we were using data from the state cancer registry, we had a large number of cervical cancer cases, thus allowing for the stratified analyses presented. In addition, we were able to examine cervical cancer mortality disparities in a large geographical region with a large proportion of rural, southeastern AA, a population that, despite its experience of much greater disparities than the rest of the United States, has been chronically understudied and therefore underrepresented in the literature.

Implications
Overall, this investigation represents an important first step in describing and defining specific populations at increased risk of death from cervical cancer. In addition, these findings emphasize the need for intervention into the myriad of factors ranging from the biological and genetic to the environmental and structural barriers impacting cervical cancer mortality. These results may help providers and other health professionals recognize the disproportionate burden suffered by AA women and suggest avenues of intervention that could reduce incidence, mortality, or both.

Summary
South Carolina (SC) has some of the largest health disparities in the nation, in particular cancer mortality rates that disfavor African Americans (AA) in comparison to European Americans (EA) with 37% higher incidence and 61% higher mortality rates for AA women compared to EA women. Consequently, the purpose of this investigation was to examine and compare the impact of race on survival among cervical cancer patients in SC.

Data from the SC Central Cancer Registry on all AA and EA cervical cancer patients in SC were analyzed for this investigation. All women greater than 19 years of age with a histopathologically-confirmed cervical neoplasm were included. Kaplan Meier survival curves were calculated and compared for each
Racial Disparities in Cervical Cancer Mortality in an African American and European American Cohort in South Carolina

21. South Carolina Central Cancer Registry

References

23. South Carolina Central Cancer Registry

Acknowledgements
The authors with to acknowledge the Community Network (SCDCN) through grant number 1 U01 CA114601-01 from the National Cancer Institute (Community Networks Program).
Racial Disparities in Cervical Cancer Mortality in an African American and European American Cohort in South Carolina


27. Social Security Administration. Death Master File. 2007. Ref Type: Data File


Cervical Cancer: A Mother’s Diagnosis and A Daughter’s Struggle to Cope

Karen Clinton

Every year in the United States, about 11,000 women learn they have invasive cervical cancer. Most of these women are younger than 55 years of age. As a community liaison, I have the privilege of meeting and interacting with people from all walks of life. I found it compelling to hear Renee’s testimony. The likelihood of any woman in her family being diagnosed with cervical cancer became a harsh reality when Renee’s mother received the news in January 2009 at the age of 53.

Renee is a 28 year-old, native of Orangeburg who moved away after college; but recently returned to this area due to the death of her sister several years ago. When asked how cervical cancer has affected her life, Renee replied, “My initial reaction to my mother’s diagnosis was…Oh my God…she’s going to die!” She added, “But I have been talking with my mother’s oncologist, reading pamphlets, and I am learning more about it.”

Renee has faced many challenges since her mother’s diagnosis. She has no help transporting her mother to and from treatments and doctor’s appointments. She also assists her mom with raising her niece in her mother’s custody. Renee had ambitions of moving back to a larger city to pursue career goals, but has had to put her dreams on hold to ensure that her mother receives the best care possible. Renee does this by making sure her mother takes her medication, attends every scheduled appointment, and eats properly. She also makes certain her niece isn’t experiencing any hindrance with her education and daily routine.

A cancer diagnosis is very stressful and often leads to anxiety and depression for patients and their families. While the events in Renee’s life are unfortunate, many families will benefit from her personal testimony. Renee has taken a proactive approach by getting a Pap exam herself. She has also educated and encouraged her aunts and female friends about the importance of getting regular Pap exams, even if they are not sexually active. Coping is easier as Renee and her family rely on their faith in God and come to understand that cervical cancer is treatable; not a death sentence.
The Epidemiological Profile of South Carolina Women Who Do Not Receive Regular Pap Test: Improving Access to Care

Shelly-Ann Bowen, MS, CT, PhD
Khosrow Heidari, MA, MS
Michael D. Byrd, MPH, LMSW, PhD
Kamala Swayampakala, MSPH
Vicki M. Young, PhD
James Jerry Gibson, MD, MPH

Background
The incidence and mortality rate of invasive cervical cancer have decreased steadily over the past several decades in both whites and African American women.1-3 As the use of the Papanicolaou (Pap) test has become more common, pre-invasive lesions of the cervix are detected far more frequently than invasive cancer.4 The American College of Obstetricians and Gynecologists, and American Cancer Society recommend that women begin cancer screening through Pap test within three years of having vaginal sexual intercourse or no later than 21 years of age whichever occurs first.5 Depending on the type of Pap test utilized and the test results, cervical cancer screening should be performed every one to two years until a woman reaches the age of thirty. Annual Pap tests are recommended until three consecutive Pap tests are interpreted as being normal, at which time the Pap test can be performed less frequently at the discretion of the provider.6-8

Access is defined as the actual use of personal health services and everything that facilitates or impedes the use of these services.20 To increase access to and participation in routine Pap tests, elements related to Pap test screening non-participation should be understood. In addition, there is a need for further studies to determine factors influencing preventive screening behaviors among at-risk populations.5, 12

More than half of the women newly diagnosed in the U.S. with invasive cervical cancer have never had a Pap test, and 10% have not been screened in the last 5 years.16 Data from the 2006 Behavioral Risk Factor Surveillance System (BRFSS) showed that only 84% of women 18 years and older reported pap tests within the previous 3 years a slight decrease from 78% in 2004.5 The target is 90% by 2010.17 A woman’s age, level of education, and financial resources are frequently associated with consistency in cervical cancer screening.8, 11, 18 Consequently, improved access to screening and early detection could increase survival rates and further lower mortality from cervical cancer.

South Carolina (SC) has an incidence and mortality rate that is higher than the national average. According to the National Cancer Institutes State Cancer Profiles, the age adjusted annual incidence rate for cervical cancer in SC from 2001-2004 was 9.1 as compared to 8.5 per 100,000 nationwide and the mortality rate is 2.9 per 100,000 compared to 2.6 of the National Average.9,10 Although the proportion of women in SC who report having a Pap test in the past 3 yrs (86.8%) is greater than the national rates (84%), National Cancer Institute (NCI) estimates 180 new cases in SC for 2008.5, 12

The Behavioral Model23, 24 was selected as the conceptual model for the study because it focuses on health care utilization at the end of a complex pattern of interaction among predisposing, enabling, need-for-care characteristics, and behavioral practices. The Behavioral Model, figure 1 has been widely used for investigating health service utilization among minority populations.20, 24-26

The conceptualization and measurement of access is pivotal to the understanding...
Conceptual Framework
Among the predisposing characteristics, demographic factors such as age and sex are biological factors that increase the likelihood that individuals will need health services. Another predisposing characteristic that help describe the propensity for health care services is social structure. Social structure is measured by a broad array of factors that determine the status of a person in the community. Measures used to assess this factor include education, occupation, and ethnicity.

The second component of the behavioral model, the enabling characteristics, refers to the individual’s ability to use health care services, should the need arise. Both community and personal enabling factors must be present for utilization to take place. First, health personnel and facilities must be available and convenient where individuals live and work. Then, individuals must have the means and knowledge of how to access the services. Income, health insurance, a regular source of care, travel, competing needs, and availability and use of information sources were identified as the enabling characteristics.

Although the predisposing and enabling components are necessary conditions for use of health services, need-for-care characteristics are the most immediate cause of the utilization of health services. That is, the individual must perceive some level of vulnerability to the illness or need for preventive care.

Methods
Survey and Sample
The BRFSS is a collaborative effort between the Centers for Disease Control and Prevention and health departments from 50 US states, the District of Columbia, and 3 territories. The BRFSS is an ongoing, state-based random-digit-dialed telephone survey of non-institutionalized population aged ≥18 with land-line telephones. Rather than collecting data on attitudes or knowledge the basic philosophy of the BRFSS is to collect uniform state-specific data on actual preventative health practices and risk behaviors linked to chronic diseases, injuries, and infectious diseases. The data on these practices and behaviors is especially useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs. For this study we examined core indicators that were measured in 2006 in SC. Analyses were limited to women ≥18 years of age with intact cervix.

Independent Variables
Independent variables included predisposing, enabling, need-for-care, and health behavior factors. Predisposing factors defined as characteristics that incline people to use health services, include socio-demographic characteristics (age, race, educational attainment, marital status, employment status, occupation, and family size). Enabling factors defined as characteristics that enable or impede use of health services, were measured using questions about the respondents’ economic and social resources (regular source of care, health insurance status, income, poverty level, inability to see a doctor because of costs in the past year, and length of time since last routine check-up).

Need-for-care variables are defined as the respondent’s perception of her health and health behavior risk factors (diet, exercise, smoking, alcohol, and HIV testing).

Statistical Analyses
A comparison of the predisposing, en-
## Table 1. 2006 South Carolina Prevalence Odds Ratio of Not Having Been Screened

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Screener</th>
<th>Non-Screener</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
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<td><strong>Age</strong>**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-44</td>
<td>89.7</td>
<td>10.3</td>
<td>1.00</td>
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<tr>
<td>45-64</td>
<td>86.16</td>
<td>13.84</td>
<td>1.4</td>
<td>1.02 - 1.95</td>
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<tr>
<td>≥65</td>
<td>76.68</td>
<td>23.32</td>
<td>2.65</td>
<td>1.87 – 3.74</td>
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<td>1.00</td>
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<td>2.29</td>
<td>1.58 – 3.33</td>
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<td>12.93</td>
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<td>1.54</td>
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<td>1.09 – 2.58</td>
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<td>8.02</td>
<td>1.00</td>
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<td><strong>Employment</strong>**</td>
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<td>Employed for wages</td>
<td>90.65</td>
<td>9.35</td>
<td>1.00</td>
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<td>Out-of-work</td>
<td>84.22</td>
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<td>80.02</td>
<td>19.98</td>
<td>2.42</td>
<td>1.76 – 3.33</td>
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<td>81.52</td>
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<td>11.35</td>
<td>1.00</td>
<td>-</td>
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<td>3</td>
<td>91.46</td>
<td>8.54</td>
<td>0.73</td>
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<td>4 or more</td>
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<td>13.96</td>
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<td>9.99</td>
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<td>2.28</td>
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<td>10.35</td>
<td>1.00</td>
<td>-</td>
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<td>76.34</td>
<td>23.66</td>
<td>2.69</td>
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<td><strong>Income</strong>**</td>
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<td>15,000 – 24,999</td>
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<td>1.89</td>
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<td>25,000 – 34,999</td>
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<td>35,000 – 49,999</td>
<td>86.64</td>
<td>13.36</td>
<td>1.44</td>
<td>0.86 – 2.44</td>
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<td>≥50,000</td>
<td>91.87</td>
<td>8.13</td>
<td>1.00</td>
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Table 1. cont’d/

<table>
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<th>Characteristics</th>
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<th>Non-Screener</th>
<th>OR</th>
<th>95% CI</th>
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<td>88.72</td>
<td>11.28</td>
<td>1.00</td>
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<td>Could not see Dr. due to Cost*</td>
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<td>Yes</td>
<td>82.45</td>
<td>17.55</td>
<td>1.67</td>
<td>1.19 – 2.34</td>
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<td>No</td>
<td>88.69</td>
<td>11.31</td>
<td>1.00</td>
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<td>Length of time since last routine check-up**</td>
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<tr>
<td>W/in the past year</td>
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<tr>
<td>W/in the past 2 years</td>
<td>91.24</td>
<td>8.76</td>
<td>1.56</td>
<td>0.98 – 2.47</td>
</tr>
<tr>
<td>W/in the past 5 years</td>
<td>61.59</td>
<td>38.41</td>
<td>10.1</td>
<td>6.62 – 5.44</td>
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<tr>
<td>5 or more years ago</td>
<td>56.69</td>
<td>43.31</td>
<td>12.4</td>
<td>8.01 – 9.15</td>
</tr>
<tr>
<td>Never</td>
<td>81.51</td>
<td>18.49</td>
<td>3.68</td>
<td>1.49 – 9.07</td>
</tr>
<tr>
<td>Need-for-care*</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Good or Better Health</td>
<td>88.54</td>
<td>11.46</td>
<td>1.9</td>
<td>1.37 – 2.64</td>
</tr>
<tr>
<td>Fair or Poor Health</td>
<td>80.26</td>
<td>19.74</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Health Behavior</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Activity*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>89.29</td>
<td>10.71</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>No (in last 30dys)</td>
<td>81.41</td>
<td>18.59</td>
<td>1.9</td>
<td>1.38 – 2.62</td>
</tr>
<tr>
<td>Body Mass Index</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither overweight nor obese</td>
<td>87.64</td>
<td>12.36</td>
<td>1.00</td>
<td></td>
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<tr>
<td>Overweight</td>
<td>88.55</td>
<td>11.45</td>
<td>0.92</td>
<td>0.65 – 1.29</td>
</tr>
<tr>
<td>Obese</td>
<td>86.7</td>
<td>13.3</td>
<td>1.09</td>
<td>0.75 – 1.57</td>
</tr>
<tr>
<td>Smoking*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking currently</td>
<td>82.04</td>
<td>17.96</td>
<td>1.74</td>
<td>1.25 – 2.41</td>
</tr>
<tr>
<td>Not smoking currently</td>
<td>88.8</td>
<td>11.2</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not binge drinker</td>
<td>87.39</td>
<td>12.61</td>
<td>1.05</td>
<td>0.63 – 1.74</td>
</tr>
<tr>
<td>Yes binge drinker</td>
<td>87.34</td>
<td>12.66</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>HIV Test**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>92.94</td>
<td>7.06</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>85.7</td>
<td>14.3</td>
<td>2.3</td>
<td></td>
</tr>
</tbody>
</table>

*p-value<0.05; **p-value<0.001

a Poverty status and Household Income: The BRFSS asks the annual household income to be classified in eight interval levels (<$10K, <$15K, ...
*.<75K, >$75K). We assumed all incomes were uniformly distribution within each income interval. To classify a family’s poverty status, we used the
poverty threshold (http://www.census.gov/hhes/www/poverty/threshld/thresh06.html) categories to assign a “Below 100% of poverty” status to each
respondent. We randomly assigned an income to each family within their income bracket. For example if there were 100 families whose income were
between $10K and $15K, the first respondents in that level was assigned an income of $10K and the second person was assigned an income of ($10K +
$5K/100)=$10,050, and so on. When a family’s assigned income exceeded the poverty threshold for their family size, then the respondent was assigned
as “Not Under 100% Poverty” and if the family’s assigned income were less than the threshold, then the respondent was assigned as “Under100%
Poverty” status.

*b Not employed for wages i.e. homemaker, retired, or student
abling, need-for-care, and behavioral characteristics between individuals who were having Pap test screening and those who were not screened was conducted using Pearson chi-square test.

To further examine the likelihood of having regular Pap test across various levels of predictors, logistic regression analysis was performed. In the univariate regression models, the dependent variable was regressed on the predisposing, enabling, need-for-care, and health behavior characteristics respectively. To determine the final model, the dependent variable was regressed on only predictors found to be statistically significant (p-value ≤0.05) using backward selection methodology. Odds ratios with 95% confidence intervals (CI) and p-values were reported. All analyses were conducted at α = 0.05 level. SAS Survey procedures were used to account for the complex survey design of the BRFSS and to calculate the estimates and 95% confidence intervals (CI).

### Results

#### Sample Characteristics

Fourteen percent (408) of all respondents to the Pap test question (2963) did not have a Pap test in the past three years. Demographic characteristics are shown in Table 1. The prevalence of Pap test screening of women in SC was 87% (CI 85%-88%). Women who did not re-

<table>
<thead>
<tr>
<th>Table 2: Multiple Logistic Regression Results for Predictors of Pap test Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td><strong>Predisposing Factors</strong></td>
</tr>
<tr>
<td><em>Age</em></td>
</tr>
<tr>
<td>45-64 vs 18-44</td>
</tr>
<tr>
<td>≥65 vs 18-44</td>
</tr>
<tr>
<td><em>Marital Status</em></td>
</tr>
<tr>
<td>Unmarried vs married</td>
</tr>
<tr>
<td><em>Employment</em></td>
</tr>
<tr>
<td>Out of work vs working</td>
</tr>
<tr>
<td>Not employed for wages vs working</td>
</tr>
<tr>
<td><em>Race</em></td>
</tr>
<tr>
<td>White Non-Hispanic vs Black Non-Hispanic</td>
</tr>
<tr>
<td>Hispanic vs Back Non-Hispanic</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><em>Family Members</em></td>
</tr>
<tr>
<td>1 vs 2</td>
</tr>
<tr>
<td>3 vs 2</td>
</tr>
<tr>
<td>4 or more vs 2</td>
</tr>
<tr>
<td><strong>Enabling Factors</strong></td>
</tr>
<tr>
<td><em>Regular Source of Care</em></td>
</tr>
<tr>
<td>0 vs ≥2</td>
</tr>
<tr>
<td>1 vs ≥2</td>
</tr>
<tr>
<td><em>Length of time since last routine check-up</em></td>
</tr>
<tr>
<td>W/in the past 2 years vs &lt; 12mths ago</td>
</tr>
<tr>
<td>W/in the past 5 years vs &lt; 12mths ago</td>
</tr>
<tr>
<td>≥5 years ago vs &lt; 12mths ago</td>
</tr>
<tr>
<td>Never</td>
</tr>
<tr>
<td><em>Health Behavior</em></td>
</tr>
<tr>
<td>Physical Activity</td>
</tr>
<tr>
<td>No vs yes in last 30 dys</td>
</tr>
</tbody>
</table>

*Model includes variables significant at p≤0.05 in bivariate analyses.
ce a Pap test were more likely to be ᵇ ≥ 65 (23.3%); unmarried (17.5%); from other non-Hispanic race groups (32%); less than high school education (24.1%); a homemaker, retired, or a student group (20%); living in a family size of one (18.4%); with an income < $15,000 (18%); under 100% poverty level (19.1%); lacking regular source of care (25.9%); without healthcare coverage (23.6%); and unable to see a healthcare provider in the past twelve months due to cost (19.2%). Women who reported not receiving a Pap test were also likely to report not accessing a health provider for a routine check-up in the past five years (43.3%) and have a perceived health status of fair or poor (19.7%). Behavioral risk results indicated that those reporting not having a Pap test were more likely to display the following characteristics: 1) have not exercised in the past thirty days (18.6%); 2) obese (13.3%); currently smoking (18%); 4) a binge drinker (12.7%); and 5) unscreened for HIV/AIDS infection (14.3%).

**Predictors of women who do not get Pap tests**

Univariate analyses of data predicting not having a Pap test in the last three years are also presented in Table 1. The subpopulations of women aged 44 – 64 years (odds ratio [OR] =1.4, 95% confidence interval [CI]: 1.02 – 1.95) and ≥65 (OR=2.65, CI: 1.87 – 3.74) were more likely not to be screened than the 18-44 years old subpopulation (reference group). Other significant predictors for not adhering to the Pap screening guidelines based on predisposing, enabling, and health behavior factors were: not employed for wages (OR = 2.42, CI: 1.76 – 3.33); unmarried (OR 2.29 CI =1.58 – 3.33); having less than a high school education (OR=3.64, CI: 2.31 – 5.75); other non-Hispanic race groups (OR = 4.83, CI: 2.35 – 9.91); having no personal health care provider (OR = 2.28, CI: 1.34 – 3.87); no health insurance (OR = 2.69, CI: 1.93 – 3.74); earning <$15,000 (OR = 2.77, CI: 1.80 – 4.29); and not tested for HIV (OR = 2.30 CI = 1.51 – 3.20).

For the final multiple logistic regression model (Table 2) we included all the significant correlates from the univariate analyses (Table 1) in a full model with three meaningful interaction terms. Using the backward selection statistical procedure, our final model included age, race, marital status, source of care, length of time since last routine check-up, perceived health status and physical activity in order of importance. Women age 65 years and older were more than four times more likely to not have a regular Pap examinations (adjusted OR = 4.60 CI: 2.62 – 8.08). Being unmarried (adjusted OR: 2.23, CI: 1.43 – 3.46); of other non-Hispanic racial groups (adjusted OR: 4.08, CI: 1.43 – 3.46); having no regular source of care (adjusted OR: 2.02, CI: 1.28 – 3.19); having no routine checkup (adjusted OR: 13.21 CI: 7.58 – 23.01); perceive good or better health (OR: 1.90, CI: 1.15 – 3.13); and not exercising (OR: 1.61, CI: 1.13 – 2.31) were significant associated with having not Pap test among women in SC.

**Discussion**

Although previous studies of cervical cancer screening have applied the Behavioral Model for Vulnerable Populations this study is unique in its focus on using the model to create an epidemiological profile of women who are not receiving Pap test screening. Of the predisposing factors, age was found to be the strongest predictor of not receiving a Pap test although all the respondents in the study were in age categories for which there are Pap test screening recommendations. It is noteworthy that the majority of the women not screened are Medicare eligible (≥65 years old); however, this is consistent with other findings that underserved women who are older were less likely to report having a Pap test and more likely to be at an increased risk of death from cervical cancer.1,16

Consistent with other studies we found unemployment to be a risk factor for not receiving a Pap test. Employment is expected to provide a source of income to the individual as well as an opportunity for accessing employer-provided insurance coverage. Without employment most individuals have limited access to affordable insurance. Ettner determined that having an HMO and level of income were both highly correlated with use of preventive services.28 Income and insurance have traditionally been correlated to higher rates of participation in Pap test screening.1,16,28
Race was also found to be a risk factor for not receiving a Pap test. This factor reflects not only issues of access to social services but also perhaps the influence of cultural and ethical decisions regarding participation in healthcare.

Length of time since last routine check-up was found to be the strongest predictor in the enabling factors category for not receiving a Pap test. Women not receiving a Pap test were less likely to have had a routine check-up in the past five years. Provider-related factors were also found to be significantly associated with not receiving a Pap test. Studies have shown that specific to cervical cancer screening, having a place for receiving healthcare has been associated with increased screening utilization. Older women are also known to rely on their providers to communicate the need for having screenings such as Pap test. This point to the urgent need for educational and motivational interventions that encourage health care providers serving underserved populations to promote cervical cancer screening among this vulnerable population.

Lack of physical activity was found to be a strong risk factor of not having a Pap test in the past three years. The literature has limited related studies that report the impact of physical activity as a predictor on screening practices. This finding warrants further studies and discussion.

Study Strengths and Limitations

There are several limitations to keep in mind. First, all data is self-reported and participants may under-report health behavior risk practices. Second, because BRFSS is a telephone survey, our results are limited to the SC population with land-line service. As a result, some groups with low socio-economic status are known to be under-represented. Third, the data is cross-sectional and cannot predict causal relationship. The major strength of the BRFSS, however, is the ability to generate population-wide estimates. The fourth limitation is that, the model presumes that the probability of non-screeners is linearly and additively related to the risk factors on the logistic scale; where as, in the real world this assumption may not be true. Our findings demonstrate an effective model to predict non-screeners and provide the opportunity for further examinations of cervical cancer screening behaviors which may assist in identifying those who are most at risk for not receiving Pap test screening and potentially more at risk of developing complications due to cervical cancer.

Implications

While the associations observed in this study do not imply a direct causal relationship between receiving a Pap test in the past three years and any of the predictors, they reflect a variety of contributing factors including predisposing, enabling, and health behavior variables. The significance of some of these variables suggests future risk related to poor access to health care and low utilization of preventive services.

Periodic evaluation of those who are not accessing care, as provided in this study, helps to identify intervention needs and opportunities for changing and improving access to healthcare delivery systems. For example, these findings indicate the importance of providers recommending Pap test to women in all age categories.

Despite best efforts from federal, state, and local levels there still seems to be a need for better access to services for those at highest risk. Programs should be intentionally developed and interventions should be shaped based upon these influencing factors. Medical providers and public health services should develop relevant strategies that will effectively target educational outreach interventions as well as enhance the collaboration between public and private sectors.

One such example of health care providers and public health working together to provide educational outreach and enhance access to care is the collaboration between the SC Department of Health and Environmental Control (SCDHEC) and the SC Primary Health Care Association (SCPHA) and its Community Health Center (CHC) membership. The partnership between public health and primary care providers offers an opportunity to link and maximize educational outreach and access to preventive and primary care for underserved populations. Public health and primary care provider partnerships ensure and strengthen the connection between health education dissemination and the provision of primary health care. Key to the success of this type of partnership is the alignment of mission and goals of the entities involved in such partnerships buy-in from all organizations involved, and the development and nurturing of the inclusive relationship with the community served.

Conclusion

In summary, this study updates and expands current literature related to factors that predict utilization of cervical cancer screening. The greatest strength of the study is the use of the Behavioral Model to create a profile of factors that predict why some women do not receive screening. Ongoing research is needed to fully explore the impact of these factors.

References


Making It Happen: Low-Income African American Women’s Follow-Up to Abnormal Pap Tests

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DeAnne K. Hilfinger Messias, RN, PhD, FAAN
Deborah Parra-Medina, MPH, PhD
Kathryn Luchok, PhD
Donna L. Richter, EdD, FAAHB

Introduction
The widespread utilization of the Pap- nicolaou (Pap) test has contributed to an overall decrease in cervical cancer mor-
tality, yet incomplete or delayed follow-
up for abnormal Pap results continues to compromise the effectiveness of cervical cancer screening.1-2 Timely follow-up for abnormal Pap tests, early diagnosis, and prompt treatment of pre-cancerous lesions and invasive cervical cancers are critical components of reducing cervical cancer mortality.3 Previous research indicates that low-income, uninsured, and ethnic minority women are at high risk for non-adherence to abnormal Pap test follow-up recommendations.4-6 The Na-
tional Breast and Cervical Cancer Early Detection Program (NBCCEDP) was in-
stituted to provide access to cervical and breast cancer screening and follow-up services for low-income and uninsured women.7 NBCCEDP data indicate dif-
ferential follow-up completion rates by race, with higher rates of no follow-up for low-grade squamous intraepithelial lesions (LSIL) among African American (AA) (25%) compared to Whites (18%) and lower rates of completed di-
agnostic evaluations for LSIL among AA (48%) compared to Whites (63.7%).8 Between 1999-2004, the cervical can-
cer mortality rates among AA women in South Carolina (SC) were twice that of White women: 5.5 per 100,000 ver-
sus 2.2 per 100,000 respectively.9 This unequal burden of disease is prevent-
able through early detection and prompt follow-up of abnormal Pap tests. South Carolina’s Breast and Cervical Cancer Early Detection Program (SCBCCEDP) data from 2000 indicated that only 59.6% of AA women with abnormal Pap tests completed timely diagnostic work-ups, compared to 70.3% of White women. In 2001, the racial gap in timely follow-up widened to a 20-percentage point difference (45.8% among AA and 65.6% among Whites).

Given the extent of cancer disparities in SC11 and the NBCCEDP’s mission of timely follow-up for abnormal Pap re-
sults, these observed patterns of lower rates of follow-up completion among AA women in the program clearly war-
rant closer examination. To date, only two studies have addressed the phenom-
enon of adherence; one was a case study of a young AA woman12 and the other a qualitative interview study conducted in Australia.13 Given the evident disparity in follow-up completion among the SCBCCEDP participants, the aim of our research was to explore the experiences of low-income AA women classified as non-adherent to follow-up for abnormal Pap test results. Using a grounded theory approach14-17, we sought to further the understanding of follow-up adherence to abnormal Pap results and contribute to the state of the science in cancer disparities.

Methods
Participant Recruitment
The research was approved by Institutional Review Boards of the University of South Carolina and the South Carolina Department of Health and Environmental Control. Inclusion criteria were AA SCBCCEDP participants who had completed a Pap test since January 1, 2003, the results of which had been re-
ported as abnormal (i.e., atypical squa-
mous cells of undetermined significance [ASCUS], LSIL, High-grade SIL, atypi-
cal glandular cells of undetermined signi-
ificance [AGUS], or invasive squamous cell cancer); had been notified of the ab-
normal result and referred for follow-up; and had been identified as being non-
adherent (i.e., completed follow-up after the benchmark of 60 days or follow-up status recorded as pending, refused or lost to follow-up). Abnormal results and non-adherence were defined according to NBCCEDP protocols.18 Participant recruitment occurred in two phases. Phase 1 involved identifying study-eligible women; obtaining consent to release their information in compli-
ance with the Health Insurance Porta-
Bility and Accountability Act (HIPAA), followed by personal contact and invita-
tion to participate in an interview (Figure
Delays in provider reporting and data entry slowed the process of identifying eligible participants; over a period of six months, 24 eligible women were identified. Written releases were received from 17 women, who were contacted and invited to participate in a face-to-face interview. In Phase 2, we used snowball recruitment to identify participants’ social contacts to further explore their influence on the follow-up completion of these SCBCCEDP women. During the interviews, SCBCCEDP participants were asked if they had discussed their Pap test with any of their family members or friends. Those who indicated they had discussed the issue with others were asked if they would be willing to contact them to obtain their consent to be interviewed. Social contacts who agreed to be contacted were then invited to participate in a telephone interview. Consistent with the principles of grounded theory, recruitment, data collection, and analysis occurred concurrently. Once there was evidence of theoretical saturation in the data analysis process, no further recruitment occurred. The complete sample consisted of 11 SCBCCEDP participants and 4 social contacts.

**Data Collection**

We developed an open-ended, semi-structured interview guide to focus the research conversations with the SCBCCEDP participants (N=11) on their experiences, perspectives, expectations, and evaluations of encounters with health care providers during the cervical cancer screening process, including receipt of Pap test results and follow-up visits. The focus of the interviews with social contacts (N=4) was on their role and participation in the SCBCCEDP participants’ decisions and behaviors related to abnormal Pap result follow-up. We conducted face-to-face, in-depth interviews with SCBCCEDP participants and used brief follow-up telephone contacts to clarify or further explore responses. All face-to-face interviews were conducted in participants’ homes and were scheduled at the convenience of the participants. They lasted between 60-75 minutes. We conducted 30-minute telephone interviews with the social contacts. All interviews were audio-taped, subsequently transcribed verbatim, and compared to the audiotapes to ensure fidelity.

**Data Analysis and Presentation**

We based the data analysis on a grounded theory approach, which involved iterative processes of open and focused coding, constant comparative analysis, and development of an explanatory model that described the underlying processes, actions, and interactions of having been advised to seek follow-up for an abnormal Pap test. The process began with an initial analysis of each individual transcript, followed by comparative cross-analyses. In addition to the interview data, interviewer field notes from telephone and personal encounters with participants provided further information and insights that contributed to the collaborative interpretation and framing of the analysis. Theoretical memos constructed throughout the research process also contributed to the process of refining and tracking emerging ideas and conceptualizations that emerged through discussions among research team members. Further in-depth analysis led to the synthesis of meaning and insights within each woman’s story.

A primary focus in presenting the data as research findings was to maintain the centrality of the storytellers’ words. To improve the readability of the transcribed speech without compromising meaning, we occasionally inserted punctuation and words or phrases for clarification, denoted by brackets and edited out extraneous and often repetitive utterances of oral speech (e.g. uh, you know).

**Results**

The study participants (N=11) ranged in age from 50-64 years (M=57.5). All resided in rural areas of SC. Three had at least a high school education; four were living with a husband or partner; seven were single, divorced, or widowed. Pap test results verified by cytological reports were distributed as follows: ASCUS (n=4); LSIL (n=3); AGUS (n=3); vaginal intraepithelial neoplasia (n=1). All SCBCCEDP participants were concurrently under treatment for other medical conditions (e.g. diabetes, hypertension, and/or cardiac conditions). The four social contacts included two daughters, a sister and a friend. We did not collect demographic information on the social contacts.

The initial record review of SCBCCEDP data indicated all participants were considered non-adherent according to program protocols, an inclusion criterion for
the study. An important finding was that in 10 of the 11 cases, this documented non-adherence actually reflected clinician non-adherent behavior (i.e., follow-up referrals were scheduled beyond the 60-day benchmark). In four of the 10 cases, the Pap test results warranted a more aggressive follow-up. The major qualitative finding revealed a complex cognitive, psychological, and social process of making follow-up happen in which these AA women were actively engaged. We identified three key elements of making it happen: acceptance, assessment, and arrangement. In the following sections we present our interpretation of how these older AA women described their experiences of making follow-up happen.

Acceptance
These women grappled with various reactions and questions before coming to terms with having an abnormal Pap test. Fear and uncertainty accompanied the abnormal test result. This was particularly the case among women with a family history of cancer, who recalled being “scared that I had cancer... my sister had it... I was scared because I might have had it.” Fear of the unknown and lack of understanding of the medical procedures contributed to reluctance to accept or acknowledge the implications of the abnormal result:

I didn’t go... I told him [doctor] I was afraid... afraid of what they were going to do, the type of test he was going to do.

Every time I go, it was the same thing... it scared me... I just got tired of going to the doctor.

However, fear did not always contribute to delayed action. Personal knowledge of the impact of cancer also served as a motivator:

I’m scared. Cancer runs in the family...I had to protect my own self because cancer runs in my family...two lives have been taken.

Uncertainty or lack of trust in clinicians’ competence contributed to delayed acceptance. This was reinforced when a participant was told to “come back to get another test” without sufficient information or explanation about the test result or need for further testing from the provider:

I wonder if they found cancer... “She did not go into detail... I assumed she [doctor] just didn’t know.

Another barrier to acceptance was complacency:

I forgot about it because... all of the others [previous Pap tests] were normal.

While concerned about the result, some women calmly accepted the abnormal Pap tests “that something was wrong and ...had to be corrected. I trust her [provider]... and I also put it in God’s hands”.

Assessment
Once the women accepted that they had abnormal Pap tests, the process of assessing potential inaction or action came into play. With an abnormal result being viewed as an intrusion into their life-world, these women began to deliberate following-up:

It’s not so easy to say, “Oh well, you know you need this...” You’re going about your normal life...this comes out of the blue. “You need this”. Why? If I don’t like it...your body is a closed environment.

Assessment involved weighing the benefits and value of going for follow-up. Use of self-talk “to figure out” and reflect on their decisions was inherent in the deliberation:

Well, just like anybody would say, “Should I go back or should I not go?”

Because is it going to make any difference if I go or don’t go? Oh, I said, “I think it’s for the best... I will go back and let him do it.”

Sometimes, I said, “I shouldn’t go” and I said “If I don’t go, I’m going to feel worse, so I better go.”

Some participants interpreted the delay of several months between the initial screening and the scheduled follow-up to signify that it was not an urgent matter: It must not be too serious. Sometimes they set you an appointment up, a month, six weeks ... then I figure I had went this long it was not going to do any more harm ...really the problem would not get any worse between that time.

The desire for more information about the diagnosis and potential prognosis motivated some women to return for follow-up:

...the possibility that something could have been wrong made me follow-up with it...I wanted to know... if they are just finding it now, if there was a problem, then my chances of doing something to get rid of it [are good].

I was saying I didn’t want to go and something tell me you better go so I figure He was the One that guided me; not man but the Lord...there is nothing that is too big for Him to handle.

In the end, after deliberating on the potential meaning of the information and the consequences of knowing (or not knowing) whether or not they had cancer, each participant actually did complete a follow-up appointment (although
Women finally go and do what they have to do. It can take a while because they think about it and pick up the courage to do this.

The women also researched information and reached out to their family and friends for support to inform their decision to follow-up:

...that was the first time I heard the word - colposcopy...they never used that word on me before ...I tried to read up on it to familiarize myself with it and I didn’t like the sound of it...

My older sister has a friend who’s a gynecologist and if there was something I couldn’t understand, she would call him and he would explain to her and he would also get on the phone and explain to me... he would call here and she would talk with him and he would also talk with me. 

Interviews with the social contacts provided insight into how their social support influenced participants’ follow-up completion. Family and friends were integral in emphasizing the importance of follow-up. They contributed by providing both logistic and emotional support:

[I made sure] that she got it [appointment] because I would always be there ... she would have transportation... I promised her and I did every time she needed to go ...as far as I was concerned I was going to make sure I was always there...

She didn’t want to go ...I used to always tell her 'Ma, if they tell you to go, you need to go – It’s important and they are not going to send you a letter to come if it’s not important.

Arrangement

For these low-income AA women, making follow-up happen required more than acceptance and assessment of the abnormal Pap test result. Arranging to complete the follow-up appointment involved adjustment and coordination of work schedules, transportation, and financing. Several women asked friends to drive them to the follow-up appointment. Having someone to accompany them to the follow-up appointment provided a sense of security when they were entering unknown territory:

I didn’t really know my way and even now, if I go back there, I would take someone...

Depending on others for transportation to a follow-up appointment meant that family members also had to rearrange their work schedules or get prior permission to miss work:

I don’t drive. I had to ask my son. I had to let him know ahead of time so he could talk to his boss man to take time to take his mum to the doctor... I had to ... let them know head of time.

When follow-up appointments were scheduled at a clinic the women were not familiar with, they depended on others for assistance:

...it’s all the way down... I had to get someone who was willing to drive ...I don’t know my way.

Having a supportive supervisor was critical in this case:

I needed to go to the lady gynecologist. She [supervisor] let me off at 11:30 to get there on time. That’s the only reason I went on for it.

Additionally, some of the women expressed concern with needed finances for the follow-up procedures:

I needed to get help... I said, “How am I supposed to come up with that? How am I going to come up with that much money?” You all will have to wait till I can raise that much money. Well, my son... had to come up with the cash.

Summary of Findings

The low-income, AA women in this research study described how, within the contexts of their own lives, they made follow-up happen. Theoretically, this complex, iterative, interconnected process revealed three core sub-processes at play prior to adhering: acceptance, assessment, and arrangement (Figure 2). For some, the initial reaction was fear and uncertainty; others were less
Discussion and Implications
A major, and unexpected, finding was that the study participants, identified as non-adherent to follow-up according to NBCCEDP clinical protocols had, in fact, actually completed follow-up as prescribed by providers. Timeliness and completeness were the two key factors that caused them to be classified as non-adherent according to SCBCEDP protocol. Ten of the 11 participants had completed follow-up within 90 days, however program protocols stipulated follow-up to be completed within 60 days of identifying the abnormal result.\textsuperscript{14} Singh et al. examined guideline adherence for women needing follow-up for abnormal cytology to determine the quality of care among clinicians in the Los Angeles County Health Care System. They measured quality of care by timeliness of work-up and appropriateness of care, which referred to the type of procedure provided relative to the clinical protocols. The findings revealed a deficiency in adherence to the guidelines for managing ASCUS and LSIL and lack of management of those with AGUS.\textsuperscript{23} While the focus of this study was not to assess the clinical management of the abnormal Pap tests, we found evidence that indicated inappropriate clinical management in about a third of the participants. Based on their results (e.g. ASCUS, LSIL, and AGUS), these women should have been scheduled for colposcopy and cervical biopsies rather than repeat Pap tests, which they received.\textsuperscript{24}

The intended finding was the result of the qualitative analysis. \textit{Making It Happen} was a complex intra- and inter-personal cognitive, behavioral, and social process these low-income AA women engaged in subsequent to notification of abnormal Pap tests and recommended follow-up. These women conducted a personal cost-benefit analysis when considering following-up, and their perceptions and life-context were pivotal to this process. Patients may process their situations in ways that may lead them to choices that are not always optimal.\textsuperscript{25} Therefore, clinicians need to i) develop skills to be aware of how patients reason and decide to adhere, ii) implement established clinical protocols, and iii) ensure patients understand the follow-up plan and procedures.\textsuperscript{25}

These findings also suggest that adherence/non-adherence is not a dichotomous behavioral concept, but rather a complex process in which women may need to accept the condition as well as question, deliberate, research, seek support, and then eventually plan and coordinate to complete the recommended follow-up. They also had to contend with informational, material and structural barriers (e.g. lack of information, finances, and transportation). These findings clearly augment the existing body of research relevant to follow-up for cervical cancer screening and move our understanding forward by providing an explanatory framework of decision-making among low-income AA women.

There are several inherent limitations of this research. The study sample was purposeful and the findings may not reflect other populations or settings. The intent of this study was to explore non-adherence within the SCBCEDP population, specifically, in low-income, rural, AA women. An unexpected finding that emerged was that the participants were, in fact, adherent, in that they did complete the follow-up that was prescribed. However, it was non-adherence to the NBCCEDP protocols on the part of providers that resulted in inappropriate or less timely follow-up.

These findings have several important practice implications. Although participants were classified as non-adherent according to SCBCEDP records, in reality they were working very hard to make follow-up happen. SCBCEDP-contracted providers currently receive training on national clinical practice guidelines and program follow-up protocols, and undergo quality assurance audits conducted by SCBCEDP staff. For professional education to be effective, they need to integrate research findings, especially those that reflect women’s perspectives into the content and delivery of the curriculum. Clinicians need to be more aware of and attuned to the informational, material, and structural barriers that contribute to delayed follow-up. Furthermore, programs and practitioners should refrain from indiscriminately labeling women who may not arrive within a prescribed time-period as non-adherent or non-compliant, because it implies that they are not actively engaged in responding to clinician recommendations. As our findings illustrated, they most likely are very engaged in the process of making it happen, within the limitations of their own resources and knowledge.

To assure adherence to SCBCEDP protocols, more targeted strategies to enhance timely follow-up as well as on-going evaluations of screening programs are needed to obtain more accurate knowledge regarding follow-up non-adherence. Given the mission of the SCBCEDP with respect to addressing cancer disparities, innovative strategies engaging clinicians in integrating program follow-up protocols into clinical practice with the BCCEDP are vital.
Embedded within these women’s experiences are complex underlying processes that include accepting and assessing the results of an abnormal Pap and arranging personal, social, logistic, and financial support needed to complete follow-up. Understanding these complex processes is therefore essential to inform women-centered interventions and institute policies to increase the rate of timely follow-up of abnormal Pap tests in this population.

References
HBCUs Inform Students and the Community about Cervical Cancer

Julian S. Green, MSW; Deloris G. Williams, RN, MSN, PhD; Dolores B. Scott, MEd; Shirley B. Madison, MS; Kimberly D. Comer, MPH; Joseph A. Haynes, BS

According to the United Negro College Fund (UNCF), the 105 Historically Black Colleges and Universities (HBCU) represent 3% of the nation’s institutions of higher learning, yet account for nearly 25% of undergraduate degrees attained by African-Americans (AA). As defined by Congress in Title III of the Higher Education Act of 1965, the primary mission of HBCU’s is the education of black Americans. An additional goal of HBCUs is the commitment to improve the community in which the institution exists. This belief was inherent in the Morrill Land-Grant Act of 1862 which provided federally-owned land to states to educate farmers, teachers, and scientists. Upon realizing a great disparity in the provision of education to AA, a second Morrill Act was passed by Congress in 1890 which declared that states integrate colleges and universities, or establish alternative institutions of higher learning for AA. The second Morrill Act had a profound impact on the AA community throughout the Diaspora. One such result was a marked increase in the prevalence of AA who attained medical attention via modern practice modalities and thereby sought to increase their knowledge of healthcare. For many students during this period, campus health centers and the university at-large provided many with their first engagement and knowledge of modern medical systems/practices. This tradition continues, as HBCU students continue to receive information regarding healthcare and well-being “best practices” from campus outlets including, but not limited to: university health centers; departmental clubs and organizations; Greek organizations; advocacy organizations; university forums and social engagement with peers and university staff.

During college, many young adults engage in their first sexual experiences, but often do so without the knowledge to make informed decisions that would support their sexual health. In an effort to determine knowledge and awareness of Human Papillomavirus (HPV), and identify effective prevention strategies at HBCUs in South Carolina, a series of informal discussions were held with students and faculty from South Carolina State University (SCSU) and Claflin University (CU) in Orangeburg, S.C., Benedict College (BC) in Columbia, S.C. and Voorhees College (VC) in Denmark S.C. Prior to the discussions, the participants completed a survey which assessed knowledge regarding HPV and cervical cancer, including how it is transmitted and diagnosed.

**Diagnosis: Testing/Detection/High-Risk Populations**

Female students were aware of the importance of receiving regular Pap tests. Both male and female students were unaware of the absence of FDA-approved HPV tests for males. Female students expressed significant discomfort and disappointment with the unknown HPV risk presented by potential male sexual partners, and stressed the importance of an HPV test for males. In response to this omission, Kia Smith, a junior at Voorhees College, stated, “It makes me feel like the healthcare system isn’t really concerned about women’s health. If men had symptoms like women, we would have had a test for men a long time ago.” Brenda Armstrong Clark, an associate professor at BC elaborated, “Unfortunately, HPV and cervical cancer have been falsely represented as a ‘women’s issue’, but we have to educate men to increase their understanding that they are also affected.” Male students concurred that an HPV test for males would further enhance levels of trust with female sexual partners and enhance relationship equity. Students were unaware that AA females in the “deep” South are infected with HPV at twice the rate of non-Hispanic white women. Sharon Daniels, an adjunct professor at VC, was not surprised by this rate, “Often times, we as AAs don’t have access to the same healthcare resources as our white counterparts; many times we cannot afford to see specialists. We go to clinics which, depending on funding and technology, may not provide the same level of service.”

**Contraction: Transmission, Symptoms and Prevention Measures**

Students overwhelmingly identified sexual intercourse as a method of transmission for HPV, however, were unaware that transmission occurs through genital skin-to-skin contact in the absence of sexual intercourse. The majority of students were unaware that transmission is possible via one incident of sexual contact and that HPV can remain undetected among women who do not obtain regular Pap tests. The majority of male and female students were unaware of the symptoms of HPV, but were aware of genital warts. Students were also aware of the importance of condoms and abstinence in reducing transmission rates, but were unaware of the length of incubation. Overwhelmingly, the majority of students at each of the colleges were reluctant to discuss their views regarding the relationship between knowledge of sexually transmitted infections (STI) and sexual behavior. Dr.
Amenti Sujai, professor of African and African American Studies at CU was not surprised by the student’s reluctance to discuss these issues. She commented, “We have to discuss how we ethically relate to each other before we can discuss these issues. In order to make them feel more comfortable, we have to begin by creating a dialogue with young people about their bodies, their sexuality and what it means to be a sexual being.”

Knowledge of Existing HPV Cure or Vaccine

Students were uncertain of the existence of a cure for HPV, but 50% of female students were aware of the HPV vaccination, Gardasil. With great frequency, female students expressed disappointment regarding insufficient awareness and prevention efforts by the healthcare system. Most male students were unaware of the existence of the HPV vaccination, and agreed with their female peers that during promotion efforts, AA female consumers should be targeted to decrease stigmatization and incidence of HPV infection. With regard to direct experience, approximately 15% of female students reported completing the HPV vaccination series prior to entering college and/or knowing someone who received the vaccination. Stacy Belin, a junior at SCSU shared, “I knew a lady who had HPV and it developed into cervical cancer. What’s so scary about it is that I don’t even think she knew that HPV could lead to cervical cancer. I know that she didn’t know about the vaccine.”

Recommendations

Based on students’ responses, four key areas, depicted in Figure 1 above left, could provide entry points to increase HPV awareness on HBCU campuses and the surrounding communities, including: 1) utilization of trained, affected peer educators; 2) collaboration with local high schools to assist with implementation of HPV education in sex education curricula; 3) the creation of HPV informational videos, which can be viewed privately or in small groups; 4) conducting an annual health forum with a sexual health component to reward students for their participation. Nearly all students that were surveyed agreed that providing an “affected” peer education program would yield the greatest benefit. Many students opined that the ability to observe and interact with affected individuals within their age group would encourage rapport and increase the likelihood of accepting new information capable of influencing their behaviors. Students also felt that HPV was either not discussed or insignificantly addressed when receiving high school sex education. Many students expressed a keen interest in the concept of receiving sexual health information in the privacy of their homes. Students stressed that informational media should be engaging and produced by individuals within their age range, utilizing “real life” situations. Dr. Shalanda Bynum, Department of Health Promotion, Education, and Behavior, University of South Carolina Arnold School of Public Health, describes the important role that culture plays in prevention efforts. Bynum stated, “Research has consistently found that culturally specific messages in prevention efforts result in a greater resonance among AA college students. Unfortunately, many of the current prevention efforts found in the media do not resonate with the AA community, as they simply do not capture the attention of AA.”

During the discussions, students also expressed a strong interest in making HPV/STI education “entertaining”. Most students agreed that the formation of an annual forum would enhance student interest and subsequent participation by decreasing the stigmatization associated with discussing sexual health in public. South Carolina State University criminal justice professor Eduardo K. Curry agrees, “We have to decrease the fear to heighten awareness.” Curry continued, “We have to remember historical events such as the Tuskegee Experiment and the rural backgrounds of many HBCU students to understand the distrust that many African-Americans still harbor.” Students also felt that such an event could be more easily promoted and better attended if combined as a joint forum and musical concert, featuring national artists. To increase student involvement, the event could be organized by students and fulfill a portion of the community service requirement in degree programs. Student participation in community service projects could support the establishment of a “revolving door”, creating the bi-directional model of assistance.
exemplified by universities and communities that function in unison. Thus, community residents could develop a greater sense of unity with the university and seek services not readily available within the smaller community.

Summary

In summary, HBCUs can no longer remain reactive, but must spearhead efforts to increase both the health of the student body, as well as the community at large. HBCUs should collaboratively initiate a “Call to Action”, whereby policies and programs could be created to aid in the prevention of HPV and other STIs. To support this action, HBCUs could more actively pursue funding sources that support both universities and the communities in which they exist. Student orientation could be redefined to include short courses in STI awareness and prevention, and be communicated in a manner that is professional, yet engaging to students. Moreover, university departments which have an interest in the health of communities should supervise these efforts. The knowledge of university faculty members within departments of Nursing, Social Work, Public Health, Rehabilitation Counseling and Physical Education should extend beyond the classroom and into the community. Clark commented, “Perhaps course content in departments could be revised to encompass an increased focus on practice skills which support awareness and prevention efforts.” Through employment, volunteerism and student internships, each of these disciplines have established relationships with the surrounding community and understand the associated critical needs. Such relationships provide the best environment for both the creation and implementation of services, and provide students with a model of how to “give back” to the community by utilizing their education.

Campus health centers should be more prevention-driven beyond the distribution of condoms and pamphlets, to collaborate with local area high schools and community-based organizations to create an information network accessible to students and community residents. Additionally, health centers should promote the availability of HPV vaccination, which depending on state of residence and age, may be free or available at a discounted cost. According to Bynum, some HBCUs have already begun to promote and provide the vaccination, “South Carolina State University is one of the HBCUs which provides the HPV vaccination and promotes HPV prevention. There has been a great initiative by their health center to focus prevention efforts on incoming freshman.”

HBCU administrations must bear in mind that beyond the campus, students will undoubtedly carry the information learned during college into the communities in which they live after graduation and moreover, utilize this information as a basis for educating their children and families. Community activist and Columbia resident Linda “T’Zima” Brown, whose 16 year-old son is considering application to Delaware State University, believes that HBCUs bear a great responsibility to the well-being of the community, “We as residents should be able to take part in the events that our black colleges have. Black colleges used to operate from a more inclusive, family approach, and we need to get back to that; plus, many HBCUs are supported with our state dollars, so the community should be able to look to them for information aside from what our children relay to us.”

References

Introduction
Genital human papillomavirus (HPV) infection is a very common sexually transmitted infection (STI) in the United States (US), and persistent high-risk HPV infection is necessary, but not sufficient to cause the most common types of invasive cervical cancer.1-7 Women of color and women living in rural geographic regions have higher incidence and mortality rates of cervical cancer compared to European American (EA) women. Decreasing disparities in cervical cancer morbidity and mortality related to HPV and the HPV vaccine on a population level. SC is characterized by high cervical cancer incidence and mortality, particularly among African American (AA) women. Innovations, such as HPV vaccines, have the potential to decrease mortality in the long term.9-10 The results from the present study may be used in the future to inform the development of culturally- and linguistically-appropriate educational interventions. In this study, we summarize findings from the first comprehensive, population-based study of cervical cancer screening and HPV among SC women.

Methods
A population-based, random-digit telephone survey was conducted in SC to assess knowledge, behaviors, and attitudes related to HPV and the HPV vaccine in June 2006.19 Knowledge of HPV and cervical cancer must be increased if the general public is to be receptive to the HPV vaccine and other emerging cervical cancer prevention and control tools.20

The purpose of this study was to evaluate knowledge, behaviors, and attitudes toward HPV and Pap test knowledge and attitudes, cervical cancer screening and sexual behavior, HPV vaccine acceptability, attitudes toward self-collection, access to health care, and sociodemographic and descriptive characteristics. Telephone interviews lasted approximately 25 minutes. At the end of the interview, participants were provided toll-free telephone numbers to obtain additional information about HPV and cervical cancer.

The survey data were first summarized with descriptive statistics, including frequencies, proportions, and means (as appropriate). Based on 19 questions, HPV knowledge scores were tested for significant differences by race using chi-square. The data were analyzed using the statistical package SAS 9.1.3.22

Results
A total of 7,937 households were called,
Table 1. Selected Sample Sociodemographic Characteristics (N=1,002)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total, n(%)</th>
<th>SC Population, US Census 2000</th>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
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<tr>
<td><strong>Race</strong></td>
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<tr>
<td>African American</td>
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<td>European American</td>
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<td>Othera</td>
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<td><strong>Age, mean age 49.1±.4 b</strong></td>
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<td></td>
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<tr>
<td>18-30</td>
<td>83</td>
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<td>31-45</td>
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<td>Unknown</td>
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*a "Other" racial categories include Asian, Native Hawaiian/Pacific Islander, and women self-identifying as a race other than US Census categories.

bSample age categories reflect HPV vaccine eligibility and differ from US Census categories.
resulting in 4,718 non-eligible households and 3,219 eligible households. Of eligible households, 1,002 interviews were completed and 27 interviews were partially completed. The response rate was 36.7% for the primary sample and 34.0% for the oversample of AA women. The 1,002 completed interviews were used for this analysis.

The sociodemographic distribution of the study population is shown in Table 1 in total and in comparison to US Census data for the state of SC. The mean age of participants was 48 years and 56.1% were EA, 40.4% AA, and 3.5% other. For this study, general findings are presented on cervical cancer screening, HPV knowledge, and HPV vaccine uptake. Almost all participants (99.5%) had heard of the Pap test, 97.8% had ever had one, and of those, 95.5% had a test in the past five years. A relatively small proportion (14.4%) reported abnormal Pap test results in the past five years and few (3.9%) reported ever having an HPV diagnosis.

Participants who reported having heard of HPV (72.8%; n=729) were asked 19 HPV knowledge items. The items, correct responses, and number and percentage of participants answering correctly are shown in Table 2. A summed score of the 19 HPV knowledge items was created with “1” assigned for correct responses and “0” for incorrect responses. Scores of 0-9 were categorized as “low” HPV knowledge and scores of 10-19 as “high” HPV knowledge. Only one respondent answered all 19 items correctly. AA participants HPV knowledge scores were significantly lower than EA participants’ ($X^2=29.184; p<.0001$).

Among participants who had a daughter between the ages of 9 and 18 (16.9%; n=169), 19.5% (n=33) reported that their daughters had already been vaccinated and 52.9% (n=72) of those who had not yet had their daughters vaccinated were willing to. Among those who did not have a daughter between the ages of 9 and 18, 65.5% (n=545) indicated that they would get the HPV vaccine for their daughter.

### Discussion
About half of the participants in this population-based telephone survey had “high” levels of HPV knowledge, yet only one participant answered all HPV knowledge items correctly. These findings are largely consistent with modest, yet improving, levels of HPV knowledge among the US population reported by other studies. There is ample room for improvement in understanding of HPV and its connection to cervical cancer and other disease outcomes.

A recent study by the Centers for Disease Control and Prevention (CDC)
found that 1 in 4 (about 25%) of 3,000 teenage girls (age 13-17) included in the study had received at least one of the three doses of the HPV vaccine (GAR-DASIL®). In this study, almost 20% of participants, which is slightly lower than the recent CDC study, with a daughter in the vaccination age range reported having had their daughter vaccinated. However, among those who had a daughter yet to be vaccinated, more than half were interested in having their daughter vaccinated. Uptake of the first HPV vaccine has been modest compared to more established vaccines required by school entry mandates.

The study has limitations. Although the study sample was moderately representative of the state, key differences in sociodemographic characteristics were noted. The sample was more urban, older, and reported higher levels of education and income compared to US Census data for SC.

Implications for Practice and Public Health

These findings reinforce the need for public health educational approaches as one component of a comprehensive effort to address the excess cervical cancer mortality in SC.

Current efforts to address cervical cancer in SC through public health awareness and education campaigns as well as larger system-level efforts are warranted to address improved, yet low, levels of HPV knowledge and modest uptake of the HPV vaccine. To avoid the noted disparities in cervical cancer in our state, particularly among AA women, public health efforts must ensure participation in cervical cancer screening, adherence to follow-up care for abnormal Pap test results, and informed decision making related to the HPV vaccine.

References

12. Sharpe PA, Brandt HM, McCree DH. Knowledge and beliefs about abnormal Pap test results and HPV among women with high-risk HPV: Results from in-depth interviews. Women Health. 2006;42(2):107-133.
Knowledge, Beliefs, and Attitudes Related to Human Papillomavirus Infection and Vaccination, Pap Tests, and Cervical Intraepithelial Neoplasia among Adolescent Girls and Young Women

Shalanda A. Bynum, MS, MPH  
PhD  
Marcie S. Wright, PhD  
Heather M. Brandt, PhD  
Judith T. Burgis, MD  
Janice L. Bacon, MD

Background
Human papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the United States (US). Estimates of prevalence among adolescent girls and young women range from 20-50% with estimates of cumulative prevalence as high as 82%. HPV is a significant threat to women’s health because of the etiologic relationship of high-risk types of HPV to cervical intraepithelial neoplasia and cervical cancer; however, the vast majority of females who test positive for high-risk types of HPV will never develop cervical cancer. Adolescent girls and young women frequently experience HPV positivity and abnormal Pap test results, but rarely high-grade cervical neoplasia or associated cancers.

There is a paucity of literature detailing psychosocial, educational, and behavioral factors related to HPV and cervical intraepithelial neoplasia among adolescent girls and young women. The importance of understanding these factors is rooted in promoting education, healthy behaviors, regular screening, and adherence to recommended follow-up care. As noted by McCree and Dempsey, additional research is needed to determine framing of HPV messages, counseling strategies for clinicians, and media outlets for message delivery. The purpose of this pilot study was to explore adolescent girls and young women knowledge, beliefs, and attitudes regarding HPV infection and vaccination, Pap tests, and cervical intraepithelial neoplasia.

Methods
This exploratory study used a two-phased, mixed-methods research approach. A purposive sample of adolescent girls and young women aged 14-20 years seeking routine gynecological care at a teen clinic in Columbia, South Carolina (SC) were recruited to participate in the study between January and April 2007. The teen clinic is located in an urban area of SC and primarily serves low-income African American (AA) adolescent females. The study questionnaire and in-depth interview guide were developed based on the literature, experience of the investigators, and previous qualitative research conducted in SC with predominantly AA women. The questionnaire included items about health care; Pap test history; HPV history; knowledge about Pap tests and HPV; sexual history; related behaviors (e.g., smoking, birth control, pregnancy); HPV vaccine beliefs; and sociodemographic questions. The in-depth interview guide included questions on general health concerns; patient-provider communication; knowledge and understanding of Pap tests, HPV, and cervical cancer; cervical intraepithelial neoplasia; and HPV positivity. The study was approved by the hospital system (Protocol #2006-87) and University of South Carolina IRBs. After the informed consent process (assent and parental/guardian consent for participants aged 14-17), participants completed a self-administered closed-ended questionnaire and participated in an in-depth, one-on-one interview with a trained female interviewer in a private room at the clinic. Audiotapes of interviews were transcribed, reviewed, analyzed, and interpreted using the constant comparison method and reviewing field notes. Open coding which involved analysis of each transcript, line by line as guided by the interview guide was conducted. During this process coding process themes were identified. Qualitative data were managed using NVivo®. Quantitative survey data were analyzed using SPSS®. Descriptive statistics were used to assess sociodemographic, educational, and behavioral characteristics of participants.

Results
Participant Characteristics
A total of 73 females completed the questionnaire and 68 completed the in-depth interview. Most participants were AA (80.3%) and aged 14-17 (67.1%), mean age 17.9 years. A majority of participants (64.6%) had public insurance
Table 1. Participants Pap Test Knowledge Responses (N=50)

<table>
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<tr>
<th>Knowledge Item</th>
<th>Correct Answer</th>
<th>% Answered Correctly</th>
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</thead>
<tbody>
<tr>
<td>A Pap test is a test to find out if you are pregnant.</td>
<td>False</td>
<td>90.0</td>
</tr>
<tr>
<td>A Pap test is a test to find out if you have a sexually transmitted infection (STI) or sexually transmitted disease (STD).</td>
<td>False</td>
<td>19.6</td>
</tr>
<tr>
<td>A Pap test is a test to find out if you have cancer in your uterus, also called your womb.</td>
<td>False</td>
<td>23.5</td>
</tr>
<tr>
<td>A Pap test is a test to find out if you have cancer in your ovaries.</td>
<td>False</td>
<td>21.6</td>
</tr>
<tr>
<td>A Pap test is a test to find out if you have cancer in your cervix.</td>
<td>True</td>
<td>84.3</td>
</tr>
</tbody>
</table>

Participant expressed: “I mean I hear people talking about HPV, but I really don’t know a lot about it”.

Patient-Provider Communication

Most participants reported positive interactions with their health care provider, while others reported difficulty in understanding what their doctors communicated to them. As one participant reported, “Sometimes, my doctor will use like those big medical words and lose me”. Participants reported that the best modality for learning about HPV and cervical cancer would come through conversations with their health care provider.

Implications for Practice and Public Health

Limited knowledge of the Pap test and HPV were consistent with published data for adolescent girls and young women.30-35 There was confusion about the purpose of the Pap test; participants knew that Pap tests detected cervical cancer, but also thought that Pap tests detected other types of cancer. Misunderstandings about the Pap test were also found in qualitative data analysis. One woman expressed that she thought an abnormal Pap test result meant that she had acquired immune deficiency syndrome (AIDS). From a public health perspective these findings are of great concern and suggest that additional efforts are needed to educate young women about the purpose of Pap tests and the meaning of abnormal Pap test results thus limiting negative psychosocial responses that have been previously reported.33-35

Another important finding is that participants thought that HPV only affected women. Participants were largely unaware that HPV was an STI which could be transmitted to both men and women during sexual intercourse. Adolescents and young adults are a population at high risk of HPV infection and HPV related health consequences such as cervical intraepithelial neoplasia.3,6 However, find-
ings suggest severe knowledge deficiencies particularly about the transmission and health consequences of HPV infection. As such, preventive behavior in the absence of knowledge is unlikely. Study results suggest that the cost of the HPV vaccine may serve as a barrier to vaccination. About 34% of participants indicated that they would not get the HPV vaccine because it costs too much. This finding is consistent with the published literature citing cost as a barrier to HPV vaccine uptake.\textsuperscript{36} Informing women and parents about available resources to offset the cost of the HPV vaccine may reduce disparities in vaccine uptake among the economically advantaged.

Table 2. Participants HPV Vaccine Perceptions (N=73)

<table>
<thead>
<tr>
<th>Question</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>It will cost me too much money to get the vaccine.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21</td>
<td>34.4</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>34.4</td>
</tr>
<tr>
<td>Don’t know</td>
<td>19</td>
<td>31.1</td>
</tr>
<tr>
<td>I don’t think it will work.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>44.9</td>
</tr>
<tr>
<td>Don’t know</td>
<td>35</td>
<td>50.7</td>
</tr>
<tr>
<td>I have a fear of needles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>8.8</td>
</tr>
<tr>
<td>No</td>
<td>26</td>
<td>38.2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>36</td>
<td>52.9</td>
</tr>
<tr>
<td>I have a fear of vaccines.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>19.1</td>
</tr>
<tr>
<td>No</td>
<td>48</td>
<td>70.6</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
<td>10.3</td>
</tr>
<tr>
<td>I don’t want to have to go back for two shots over 4-6 months.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>3.1</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
<td>69.2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>18</td>
<td>27.7</td>
</tr>
<tr>
<td>I have no transportation to the clinic.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15</td>
<td>22.1</td>
</tr>
<tr>
<td>No</td>
<td>36</td>
<td>52.9</td>
</tr>
<tr>
<td>Don’t know</td>
<td>17</td>
<td>25.0</td>
</tr>
<tr>
<td>I am afraid of what people would think of me if I get it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>19.1</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
<td>67.6</td>
</tr>
<tr>
<td>Don’t know</td>
<td>9</td>
<td>13.2</td>
</tr>
<tr>
<td>My parent or caregiver will not agree with me getting this vaccine.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>14.1</td>
</tr>
<tr>
<td>No</td>
<td>49</td>
<td>76.6</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6</td>
<td>9.4</td>
</tr>
<tr>
<td>I can not talk to my parent or caregiver about sex or ways to protect myself from HPV.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>10.8</td>
</tr>
<tr>
<td>No</td>
<td>38</td>
<td>58.5</td>
</tr>
<tr>
<td>Don’t know</td>
<td>20</td>
<td>30.8</td>
</tr>
</tbody>
</table>
and disadvantaged. Many low-income patients attend the teen clinic. There is a great concern that those experiencing the greatest disparities in HPV infection and cervical cancer, including economic disadvantaged and minority groups, will not benefit equally from the promise of the HPV vaccine and will continue to suffer excess cervical cancer mortality.  

Most participants reported positive interactions with their health care provider and preferred that information about HPV come from their provider. This finding underscores the relevance of the clinical setting in providing age-appropriate, accurate information to adolescents who have demonstrated interest and motivation by seeking gynecological care. Young women trust the information and recommendations provided by their health care provider. This is an important finding in that effective patient-provider communication addresses misunderstandings about Pap tests, HPV, and cervical cancer. Effective communication also increases patient’s satisfaction and is associated with positive health outcomes and, therefore, key to addressing cervical cancer in SC and beyond. Study findings indicate that the clinical setting provides a unique opportunity to build relationships with young women and provide important information about Pap tests and HPV. The findings reported here and the growing body of literature regarding HPV should lead to more concentrated areas of focus for clinic-based disease prevention and health promotion efforts for adolescents and young adults.

This pilot study has limitations that should be considered when interpreting study results. First, the small sample size limited the examination of predictors of HPV and Pap test knowledge and HPV vaccine beliefs. Second, the study included a purposive sample of adolescent girls and young women; results may not be representative of the larger population. This study also has major strengths. First, a mixed-method research design was used, which allowed for a more in-depth exploration of adolescents girls and young women beliefs about HPV and Pap tests. Second, a large number of AA females were included, a population that is underrepresented in the HPV literature and for which little is known. Based on the findings of this pilot study, there seems to be a need for age-appropriate educational efforts designed to prevent possibly harmful psychosocial responses to cervical intraepithelial neoplasia and HPV while promoting education, healthy behaviors, regular screening, and adherence to recommended follow-up care. The clinical setting seems ideal for this type of effort.

### References
2. Weinstock H, Berman S, Cates W. Sexu-

### Table 3. Participants HPV Knowledge Responses (N=28)

<table>
<thead>
<tr>
<th>Knowledge Item</th>
<th>Correct Answer</th>
<th>% Answered Correctly</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are many types of HPV.</td>
<td>True</td>
<td>25.0</td>
</tr>
<tr>
<td>HPV causes HIV/AIDS.</td>
<td>False</td>
<td>46.4</td>
</tr>
<tr>
<td>Antibiotics can cure HPV.</td>
<td>False</td>
<td>17.9</td>
</tr>
<tr>
<td>You can always tell when someone else has HPV.</td>
<td>False</td>
<td>17.9</td>
</tr>
<tr>
<td>HPV can cause abnormal Pap tests.</td>
<td>True</td>
<td>39.3</td>
</tr>
<tr>
<td>Only females (women) get HPV.</td>
<td>False</td>
<td>0</td>
</tr>
<tr>
<td>HPV causes herpes.</td>
<td>False</td>
<td>25.0</td>
</tr>
<tr>
<td>HPV can affect a female’s (woman’s) ability to get pregnant.</td>
<td>False</td>
<td>3.6</td>
</tr>
<tr>
<td>HPV is a virus.</td>
<td>True</td>
<td>7.1</td>
</tr>
<tr>
<td>HPV causes genital warts.</td>
<td>True</td>
<td>28.6</td>
</tr>
<tr>
<td>You can have HPV without knowing it.</td>
<td>True</td>
<td>10.7</td>
</tr>
<tr>
<td>HPV is a sexually transmitted infection.</td>
<td>True</td>
<td>17.9</td>
</tr>
<tr>
<td>HPV may go away by itself</td>
<td>True</td>
<td>71.4</td>
</tr>
<tr>
<td>HPV can cause cervical cancer.</td>
<td>True</td>
<td>17.9</td>
</tr>
<tr>
<td>A female (woman) can get HPV by not keeping herself clean.</td>
<td>False</td>
<td>3.6</td>
</tr>
<tr>
<td>Only women can be tested for HPV.*</td>
<td>True</td>
<td>75</td>
</tr>
</tbody>
</table>

*At the time of the study, there were no FDA-approved methods of clinically testing men for HPV DNA. Both men and women could be diagnosed through visual inspection and visual inspection with acetic acid. However, only women could be diagnosed with HPV DNA, particularly high-risk HPV, in a clinical setting.


28. NVivo® qualitative data analysis program version 2.0 [computer software] [computer program]. Melbourne (AU): QSR International Pty Ltd; 2000.

29. SPSS for Windows, Rel. 16.0 [computer program]. Chicago IL: SPSS, Inc; 2008.


Knowledge, Beliefs, and Attitudes Related to Human Papillomavirus Infection and Vaccination, Pap Tests, and Cervical Intraepithelial Neoplasia among Adolescent Girls and Young Women


Daily, a mixture of questions loom in your head: Is she really ready for her license? What is she wearing? Can I trust her friends? Is she safe?

Parents and their teenaged daughters, in many ways, are constantly resolving issues as it relates to driving, clothes, allowances, and her peers. Now more than ever parents are faced with considering the latest advances in cancer prevention which result in “Should she be vaccinated against cervical cancer?” Below is an account of how one mother has answered that question with help from a surprising source, her daughter.

I, too, faced this decision. I am a single mother of a seventeen year old young lady who is within the recommended age range for vaccination. Many of the challenges that I encounter on a daily basis help ensure that my daughter gets the most out of her adolescent years, and ultimately, prepares her for her rapidly approaching adulthood. When it came to having to decide whether to vaccinate, I felt it was only fitting to include her input on the matter. This (vaccine) affected her life; it was her getting the shot(s). I wanted to hear what she had to say. Including her teaches her skills to make decisions about her health and livelihood as an adult. I didn’t want to miss this opportunity.

It was easy starting this conversation:

Maleiah is an active teen who works as a peer educator for a local organization, helping promote HIV/AIDS prevention and awareness to other teens in the community. She understands what prevention means and how valuable it can be.

“Maleiah, I’ve been thinking about getting you the vaccine for HPV (Human Papillomavirus). Have you heard about it?”

She had. She knew that there are three doses and that it could protect her from cervical cancer. Many youth understand the commercials that they see on TV, but are not able to make the decisions about their own health. It is our job, as parents, to weigh the pros and cons and recognize that an ounce of prevention is worth more than our daughters being susceptible to a cancer that can kill them. It’s empowering to know that she helped decide to get the vaccine and that this could be the continuation of healthier lifestyle decisions made by her.
Pap Test and HIV Testing Behaviors of South Carolina Women 18-64 Years Old

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Lucy Annang, PhD, MPH
Donna L. Richter, EdD, FAAHB
Myriam E. Torres, PhD, MSPH
Edith M. Williams, PhD, MS
Saundra H. Glover, PhD, MBA

Background and Significance
Oncogenic genital human papillomavirus (HPV) infection has been identified as the main etiological cause of cervical cancer.1,2 Studies have shown that women with human immunodeficiency virus (HIV) have a high prevalence, incidence, and persistence of HPV infection.3-7 Because of the elevated risk of HPV-associated cervical cancer among women with HIV/AIDS,8 the early detection of both HIV and cervical abnormalities will play a vital role in reducing incidence and mortality rates for these diseases which disproportionately affect African American (AA) women.9

Papanicolaou (Pap) tests are used to detect cellular changes in the cervix. There is a growing debate in the scientific literature over the use of HPV DNA testing either alone or in conjunction with (i.e., co-testing) the cytological exam.10-13 Nonetheless, the Pap test remains a useful screening tool for the prevention of cervical cancer. Current screening guidelines recommend routine Pap tests for women three years after sexual debut, but no later than age 21.14 Behavioral Risk Factor Surveillance System (BRFSS) data suggest that among women 18 years and older residing in South Carolina (SC) in 2006, 96.1% reported that they had received a Pap test.15 These findings show that just past the mid-year review, SC was very close to meeting the Healthy People 2010 objective for 97% of women 18 years and older to have ever had a Pap test.16

On the other hand, with regard to HIV testing the news was not so good. Only 35.4% percent of women (18-64 years old) from SC who participated in the 2006 BRFSS survey reported that they have ever been tested for HIV.15 Even more alarming is the fact that unlike other AIDS-defining cancers such as Kaposi's sarcoma and Hodgkin’s lymphoma, the incidence of invasive cervical cancer among women with HIV/AIDS has not decreased with the arrival of highly active antiretroviral therapy (HAART).7,17 These data underscore the importance of early diagnosis of HIV as women diagnosed with both AIDS and cervical cancer do not do as well as those who have an intact immune system.8 Thus, it is imperative that women learn their HIV serostatus as soon as possible so that those who are infected with HIV can initiate treatment early to prevent (or at least delay) the progression to an AIDS diagnosis.18-20 As the incidence and prevalence of HIV/AIDS continues to increase among females,21 it will become increasingly important to ensure that women are screened for both cervical cancer and HIV.

The Centers for Disease Control and Prevention (CDC) revised its recommendations for HIV testing to include all persons 13-64 years old regardless of risk. The goal is to increase the number of persons who are aware of their HIV status by offering HIV testing where other diagnostic tests and routine screenings are performed.19 Subsequently, the American College of Obstetrics and Gynecology (ACOG) recently released a formal committee opinion that supports the CDC revised HIV testing guidelines. The ACOG recommends that women between the ages of 19 and 64 years old be tested for HIV as a routine part of gynecological care.22 The purpose of this study was to describe Pap testing behaviors among women in SC and examine these behaviors in relationship to HIV testing. We hypothesized that women who had ever had a Pap test will be more likely to have also been tested for HIV.

Methods
The BRFSS telephone-based survey was administered to a sample (n=414,509) of non-institutionalized adults 18 years and older in the United States (US), Guam, Puerto Rico, and the US Virgin Islands.23 Participants were randomly selected from a sample of all telephone-equipped households, with post-stratification adjustments made for selection and response bias. Data were weighted annually according to state-specific demo-
analyses were performed using weighted Chi-square tests and logistic regression. Statistical Analysis

Based on the Healthy People 2010 goal, the goal for Pap testing was to describe Pap test behaviors among participants (18-64 years old) in SC. Associations between Pap testing and HIV testing behaviors were also examined. SAS version 9.2 (SAS Institute Inc., Cary, NC, USA) was used to perform these analyses on the weighted data.

Havign ever had a Pap test was the dependent variable or outcome. Having ever been tested for HIV was used as the main independent variable or exposure in the subsequent logistic regression analyses in which having ever had a Pap test was modeled. First, behavioral associations between the outcome and exposure were examined. Next, associations between the outcome and the covariates were assessed using simple logistic regression models. Similar associations were examined between the exposure and each of the covariates in which having been tested for HIV was modeled.

Covariates associated with both the outcome (ever had a Pap test) and the exposure (ever had an HIV test) were assessed for confounding in the subsequent multivariate logistic regression analyses. Variables were removed in a backward stepwise fashion. If the odds ratio of the exposure (having ever been tested for HIV) was changed by more than 10%, the variable was kept in the model as a potential confounder of the relationship between Pap and HIV testing behaviors. Otherwise, variables were removed one at a time until all remaining variables were either significant based on an alpha level of significance less than 0.05 or could not be removed because it was a potential confounder. The odds-ratio, 95% confidence interval, and p-value for these behavioral associations are reported.

Outcome Variables

Our primary outcome of interest was whether or not participants had ever had a Pap test. This was assessed by participants' response to the following BRFSS question: Have you ever had a Pap test? Responses were dichotomized as “yes” or “no”. The secondary outcome of interest was whether participants had ever been tested for HIV. This was assessed by participants’ response to the following BRFSS question: Have you ever been tested for HIV? Participants were instructed to exclude HIV testing that was done as part of a blood donation and include rapid HIV testing that used fluid from their mouth. Response options were “yes” or “no” which were recoded as “tested” or “not tested”. Participants who responded don’t know/not sure or refused to answer these two items were excluded from the analysis.

Covariates

Sociodemographic characteristics (age, race/ethnicity, marital status, education, employment, poverty status, and urbanization) and healthcare access (insurance, personal doctor, affordable healthcare, and routine medical checkup) variables were used to describe sample characteristics as well as control for potential confounding between the outcome (having ever had a Pap test) and the exposure (having ever had an HIV test) in the multiple logistic regression models.

Results

Pap Testing Behaviors

A majority (97%) of participants between the ages of 18 and 64 who completed the 2008 SC BRFSS survey reported ever having a Pap test. Participants between 25 and 34 years old had similar proportions for those reporting they had ever had a Pap test (28%) and those who had never had a Pap test (30%). However, almost half (47%) of participants who had never had a Pap test were between 18 to 24 years old. Compared to the proportion of participants 35-49 years old (9%) and 50-64 years old (14%) who had never had a Pap test, a larger proportion of participants in these age groups reported that they have had a Pap test, 35% and
### Table 1. Characteristics of SC women (18-64 years) by Pap test (n=3,404), BRFSS 2008

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Pap Test</th>
<th>No Pap Test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Total</td>
<td>3321</td>
<td>97</td>
</tr>
<tr>
<td>Age Category (yrs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>94</td>
<td>6</td>
</tr>
<tr>
<td>25-34</td>
<td>443</td>
<td>28</td>
</tr>
<tr>
<td>35-49</td>
<td>1170</td>
<td>35</td>
</tr>
<tr>
<td>50-64</td>
<td>1614</td>
<td>31</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>NH white</td>
<td>2151</td>
<td>70</td>
</tr>
<tr>
<td>NH black</td>
<td>1170</td>
<td>30</td>
</tr>
<tr>
<td>Marital Status</td>
<td>**</td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>1917</td>
<td>68</td>
</tr>
<tr>
<td>Divorced/separated/widowed</td>
<td>903</td>
<td>16</td>
</tr>
<tr>
<td>Never married</td>
<td>494</td>
<td>16</td>
</tr>
<tr>
<td>Missing</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Educational Level</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Did not graduate from high school</td>
<td>253</td>
<td>6</td>
</tr>
<tr>
<td>High school graduate</td>
<td>1046</td>
<td>29</td>
</tr>
<tr>
<td>Some technical school/college</td>
<td>974</td>
<td>33</td>
</tr>
<tr>
<td>Technical school/college graduate</td>
<td>1047</td>
<td>32</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Employeda</td>
<td>2380</td>
<td>70</td>
</tr>
<tr>
<td>Unemployedb</td>
<td>937</td>
<td>30</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Federal Poverty Guidelines (%)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Poverty Statusc</td>
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<td></td>
</tr>
<tr>
<td>&lt;100</td>
<td>523</td>
<td>17</td>
</tr>
<tr>
<td>125-200</td>
<td>757</td>
<td>22</td>
</tr>
<tr>
<td>&gt;200</td>
<td>2040</td>
<td>61</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Urbanization</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>MSA (urban/suburban)</td>
<td>1971</td>
<td>75</td>
</tr>
<tr>
<td>non-MSA (rural)</td>
<td>1350</td>
<td>25</td>
</tr>
<tr>
<td>Health Care Accessd</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had health insurance (REF)</td>
<td>2729</td>
<td>82</td>
</tr>
<tr>
<td>Had a personal doctor (REF)</td>
<td>2978</td>
<td>89</td>
</tr>
<tr>
<td>Was able to afford needed healthcare (REF)</td>
<td>2596</td>
<td>78</td>
</tr>
<tr>
<td>Had a routine medical checkup (REF)</td>
<td>2343</td>
<td>69</td>
</tr>
<tr>
<td>HIV Testingg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tested</td>
<td>1271</td>
<td>43</td>
</tr>
<tr>
<td>Not tested</td>
<td>2050</td>
<td>57</td>
</tr>
</tbody>
</table>

*P<.05, **P<.0001, NS not significant, P>.05; *includes self-employed and retired; †includes homemakers and students; ‡based on the USDHHS 2008 Federal Poverty Guidelines; ‡within the past year; *excludes HIV testing done as part of blood donation; includes oral (rapid) HIV test
31% respectively. These differences were statistically significant (p<0.0001) as reported in Table 1.

**Sociodemographics**
Among participants who reported that they had ever had a Pap test, the majority were married or had a partner (68%). Whereas the majority of participants who reported they had never had a Pap test had never been married (73%). This data are reported in Table 1 and are also statistically significant (p<0.0001). For other sociodemographic characteristics such as race/ethnicity, educational attainment, employment status, poverty status, and urbanization there were no statistically significant differences between the proportions of participants who had ever had a Pap test compared to those who had never had a Pap test. This data is also reported in Table 1.

**Healthcare Access**
While there were no statistically significant differences between the proportion of participants who reported that they had ever had a Pap test and those who had never had a Pap test based on their ability to afford needed healthcare (p=0.1536) within the past year, there were statistically significant differences for other healthcare access issues in the past year such as having health insurance (p=0.0001), a personal doctor (p<0.0001), and a routine medical check-up (p=0.0019). Most of the participants who had a Pap test had health insurance (79%), at least one personal doctor (89%), and a routine medical checkup (69%) within the past year. This data are reported in Table 1.

**HIV Testing Behaviors**
There were statistically significant differences in HIV testing behaviors between the proportions of participants who had ever had a Pap test and those who had never had a Pap test (p=0.0010). Although the majority of participants who had ever had a Pap test had never been tested for HIV, 43% who reported that they had ever had a Pap test had also been tested for HIV. Among the participants who had never had a Pap test, the vast majority of them (80%) had never been tested for HIV. These data are reported in Table 1. After adjusting for age, race/ethnicity, marital status, educational attainment, percent federal poverty guidelines, urbanization, and having health insurance within the past year, participants who had never been tested for HIV were less likely to report that they had ever had a Pap test (OR 0.50, 95% CI 0.28, 0.89) (See Table 2).

In addition to observed differences in HIV testing behaviors by participation in Pap testing, we also observed statistically significant differences in HIV, testing by age groups (p<0.0001). Of the 42% of the participants (n=1,298) that reported that they had been tested for HIV only 8.1% were between the ages of 18-24 years old. The majority of the participants that had been tested for HIV were between 25 and 49 years old, with 38% of those 25-34 years old and 38% of those 35-49 years old reporting that they had been tested for HIV. However, only 16% of women aged 50 years and older reported that they have ever been tested for HIV.

**Discussion**
The participants in this study met the Healthy People 2010 target for 97% of all women 18 years and older to have ever had a Pap test.16 This data are consistent with previous years since women in SC have been progressing towards the Healthy People 2010 goal and near the mid-year review, had nearly met the 97% target.15,28 Although Oster et al.27 found Pap testing to be negatively associated with increasing age, this was not the case in our study. There were similar proportions of women 50 years and older that reported having ever had a Pap test compared to women in the 25-34 and 35-49 age groups. Nonetheless, when examining Pap testing behaviors especially among populations that are disproportionately burdened by cervical cancer, it is important to keep in mind that although higher Pap testing rates may be reported among minority women, this group of women continues to have disproportionately higher incidence and death rates of cervical cancer. As a case in point, data reported by CDC on the top ten cancers in 2005 for SC only included African American women for both cervical cancer incidence and death for which they ranked 10th and 7th respectively with age-adjusted incidence (9.3 per 100,000) and mortality (5.5 per 100,000).28

In contrast to these Pap test findings, only 42% of the women in this study have ever been tested for HIV. This data

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Pap test (n=3,308)</th>
<th>No Pap test (n=82)</th>
<th>Odds-Ratio (OR)</th>
<th>Adjusted Odds-Ratio (AOR)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Ever tested for HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tested</td>
<td>1267</td>
<td>43</td>
<td>27</td>
<td>20</td>
</tr>
<tr>
<td>Not tested</td>
<td>2041</td>
<td>57</td>
<td>55</td>
<td>80</td>
</tr>
</tbody>
</table>

*P<.05
\[n=3,390 after excluding observations with missing values for either the response or explanatory variables
\[after adjusting for age, race/ethnicity, marital status, education, poverty status, urbanization, and health insurance
are somewhat consistent with previous years (2001-2006) where HIV testing rates among women in SC ranged from 35.4% to 53.3%\(^7\), albeit still a long way from reaching the CDC’s goal of all persons knowing their HIV serostatus.\(^8\) Although providers have not fully implemented the ACOG’s revised recommendations\(^9\) to date, the ACOG’s support of these revised HIV testing guidelines will hopefully increase the adoption of routine HIV testing practices during regular gynecological care visits.\(^10\) Subsequently, our finding that women who have ever had a Pap test were more likely to have also been tested for HIV suggest further research is needed to explore how Pap tests may be used to facilitate HIV prevention efforts to reduce the incidence and mortality rates of both cervical cancer and HIV/AIDS. These data are especially relevant given recent findings of Oster et al.\(^11\) that routine cervical cancer screening (i.e., annual Pap test) is suboptimal among women infected with HIV. This evidence is particularly concerning given the increased risk of cervical cancer among women with HIV/AIDS\(^12\) which has not been shown to be decreasing in the era of HAART.\(^13\)

**Strengths and Weaknesses**

A major strength of this study is the fact that both Pap and HIV testing behaviors were assessed from the same individuals at the same time. The BRFSS which is a large nationally representative survey allowed for the examination of the relationship between HIV testing and routine gynecological screening procedures (i.e., Pap test) post the CDC’s 2006 revised HIV testing recommendations. To date there are no published studies that have examined the relationship between these two preventive health behaviors among both HIV-negative and HIV-positive persons. Our findings for women 18-24 years old may be limited as the study’s participants were sampled from households with land-line telephones and this age group is increasingly using only cell phones. Thus, we suspect that HIV testing rates for this age group are underreported. However, the fact that this age group had the lowest Pap testing rates is not surprising given current Pap test screening recommendations of being screened by age 21 and previous reports of low Pap test screening rates in this population.\(^14\) We are further limited by the study’s design in that both of the outcomes of interest were self-reported. However, Ferrante et al.\(^15\) recently reported 61% congruence between self-reported cervical cancer screening and medical records data. Therefore, self-reported Pap testing behaviors may not be a limitation of this study. In addition, HIV-status was not reported which would have facilitated being able to assess cervical cancer screening behaviors for women infected with HIV.

**Implications for Practice and Public Health**

The CDC estimates that about 21% of all HIV infected persons living in the US are unaware of their serostatus.\(^16\) In response to this public health threat, the CDC revised its HIV testing guidelines and currently recommends that all adolescents/adults between the ages of 13-64 years old be tested for HIV, regardless of risk. To meet this goal, the CDC proposed that an HIV test be offered routinely as part of other routine diagnostic and screening procedures. Our state’s success with Pap testing may represent an opportunity to increase HIV testing among women. This is of particular importance to AA women living in SC who are disproportionately burdened by both cervical cancer and HIV/AIDS.\(^17\)

Our findings suggest additional research is needed to further examine the relationship between Pap and HIV testing behaviors. Given SC’s overall success with cervical cancer screening, linking Pap testing with HIV testing during routine health visits may facilitate meeting the CDC’s goal of increasing the number of persons who know their HIV status.\(^18\) Given the fact that older women (50+ years old) in this study had a lower HIV testing rate, studies\(^19,20\) and epidemiological data\(^21\) have shown that this age group is more likely to receive a late HIV diagnosis; healthcare providers should ensure that their HIV test offering practices also include this population. Increasing HIV prevention efforts aimed at meeting the specific cultural needs of older women are warranted given the growing incidence and prevalence of HIV/AIDS among older adults\(^22\) and the dearth of HIV prevention programs that target this population.\(^23\) The fact that the older women in our study had similar Pap test screening rates when compared to women 25-49 years old suggest further that these routine gynecological exams may represent potential missed opportunities to target this group with HIV prevention messages.

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Introduction

Worldwide, cervical cancer is the second most common cancer affecting women and the leading cause of cancer mortality in developing nations. Human papillomavirus (HPV) is the cause of genital warts, cervical dysplasia and cervical cancer.1-3 Since the advent of the Papanicolaou (Pap) test fifty years ago, cervical cancer has become one of the most screened for and therefore preventable cancers. The cervical cancer mortality rate in South Carolina (SC) ranks eighth in the nation with 1623 new cases and 668 deaths from 1996–2003. When stratified by race, cervical cancer is the fifth most common cancer in African American (AA) women and the ninth most common among Caucasian women. Across the United States (US) the incidence of cervical cancer is 50% higher in AA women and 66% higher in Hispanic women with mortality rates two-fold higher than found in Caucasian women.4-9

Racial disparities in cervical cancer incidence and morality can in part be attributed to differences in screening and access to health care, but after controlling for these factors, AA and Hispanic women still continue to have higher cervical cancer incidence and mortality rates.4-10 This is presumably due to differences in acquisition and clearance of HPV, the etiologic agent of cervical dysplasia and cancer. Current methodologies examining Pap tests, cervical biopsies and HPV status cannot predict which women will develop cervical cancer and which women will spontaneously regress, rendering treatment inefficient.9-10 In this study, we examined medical and lifestyle factors that have a high prevalence in SC, in particular among AA women.

SC ranks eighth in the US for percentage of residents with diabetes and ninth for deaths secondary to diabetic complications. Diabetes disproportionately affects AAs and Hispanic women when compared to Caucasians.11-12 In SC, minorities are two times more likely to be diagnosed with diabetes and three times more likely to die from complications of diabetes.13-14 Uncontrolled hyperglycemia and long standing diabetes causes damage to a multitude of organ systems leading to increased cardiovascular disease, elevated infection rate, neuropathy and impaired kidney function secondary to microvascular and macrovascular damage.15,16 Given the adverse affects of diabetes and the high rates in AAs and Hispanics, it may possibly impact the clearance and progression of HPV.

Obesity is another major health issue in SC with 27.8% of the population characterized as obese in 2007; SC ranked fifth in the nation in 2007 according to the Centers for Disease Control and Prevention (CDC). Additionally, the rates of obesity in AAs and Hispanics are significantly higher than Caucasians in SC.17-18 AA women have the highest proportions of obesity with 44.8% obese whereas only 19% of Caucasian women are obese. Although obese women are known to have higher mortality rates for cervical cancer than normal weight women19-20, the relationship between cervical dysplasia, HPV clearance, and obesity is not known.

Lastly, teen pregnancy in the US as well as in SC had been falling steadily until 2004; from 2004-2006, there was a 8% jump in teen pregnancy rates in SC.22 The rates of teen pregnancy continue to be 50% higher in AA women as compared to Caucasian women. Shields et al (2006) showed a slight trend towards increased cervical cancer risk with multiparity. When this was adjusted by age at first live birth, the association became less robust.23 The affect of teen pregnancy (live birth, miscarriage, or termination) on the development and progression of cervical dysplasia has not been studied.

In this brief report, we examined how diabetes, body mass index (BMI), smoking, and history of teen pregnancy affect the cervical pathology after an HSIL Pap test given the high prevalence in SC. These modifiable medical and lifestyle factors may help to predict the likelihood of having CIN 2/3 on colposcopy-directed biopsies after an HSIL Pap test result.

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Methods
IRB approval was obtained through Palmetto Health Institutional Review Board for this retrospective review. Charts of all patients with HSIL Pap results at Palmetto Health Women’s Center Columbia, SC 2005–2007 were identified and reviewed; there were no exclusion criteria. A total of 89 women were identified. Data analysis was performed by standard statistical analysis (t-test, x²) computer programming. Null hypotheses were rejected for p values < 0.05.

Results
Given the diverse population of Columbia, SC, there is a large proportion of minority patients at Palmetto Health Women’s Clinic. In 2007, the ethnic distribution was 67% AA, 13% Caucasian, and 17% Hispanic (Figure 1A). The women who receive care at the health center tend to be living at or below the poverty line; many with only grade school education and poor literacy skills. Most have Medicaid or lack health care insurance altogether. In 2007, 88% had Medicaid/Medicare or were self-pay.

A total of 89 women were identified as having an HSIL Pap test result from 2005–2007. The ethnic distribution of the women with HSIL is shown in Figure 1B; AA women comprised 75% of these patients; 17% were Caucasian and 6% were Hispanic. The average age of women with cervical HSIL from 2005–2007 was 26.8±7.7 with a range from 15-59. The age distribution was similar to that of all women seeking care at Palmetto Health Women’s Clinic in 2007 (26.8±9.4).

All of our patients with a HSIL Pap test result were referred to a colposcopy clinic for further evaluation. On subsequent colposcopy-directed biopsies 40% of women with HSIL Pap tests had CIN 2/3 and 33% had CIN 1. Disturbingly, 27% of these patients were lost to follow-up and never had a colposcopy performed (Figure 2). The average age of women...
with CIN 2/3 was 28.7±9.3 whereas the average age for CIN 1 and those lost to follow-up was 25.4±7.8 and 25.8±4.3. These differences were not statistically significant (p-values 0.13 and 0.11 respectively).

The first medical risk factor examined was diabetes. In our population, five women had diabetes. On subsequent cervical biopsies, three women had CIN 2/3 and one had CIN 1; one patient was lost to follow-up. All women with diabetes were AA. This suggests a possible association between diabetes and severe dysplasia and warrants further investigation with a larger population stratified by diabetes type (Type 1, Type 2, or gestational diabetes) and how well hyperglycemia is controlled by examining HbA1C trends.

The next variable studied in relationship to cervical dysplasia was obesity (figure 3). The average BMI in our study population was 28.7±8.0 with 55% overweight or obese (BMI > 25). There was no statistical difference in BMI among women who were lost to follow-up (28.9±7.3) as compared to the women with CIN 1 (27.5±6.5) or CIN 2/3 (29.6±9.5). There was no statistical difference in the BMI of women with CIN 1 versus CIN 2/3 (p = 0.14). When this data was further stratified by severity of dysplasia on cervical biopsy, we observed that CIN 2/3 was associated with extremes of weight (BMI < 18.5, >30). In total, 75% of underweight patients and 68% of obese patients had CIN 2/3 on subsequent cervical pathology. There were only four women with a BMI < 18.5 so, no statistical analysis was performed of this subset. The obese women had a two-fold greater chance of having CIN 2/3 as opposed to CIN 1 on cervical biopsy following HSIL (p<0.05). This difference was not observed in normal weight (BMI, 18.5–24.9) and overweight (BMI, 25–29.9) women (Figure 3). It is unclear why women at the extremes of weight would have a higher risk for CIN 2/3; nutritional status may play a role.

Smoking is a well known risk factor for abnormal Pap tests, HPV persistence, and cervical cancer.25-26 Only thirty-eight percent (n=34) of the study population smoked. There was no racial difference in smoking rates (data not shown). Among smokers with cervical HSIL, 38% had CIN 2/3 and 62% had CIN 1; among non-smokers, 64% had CIN 2/3 and 36% had CIN 1. When this data was stratified by CIN 2/3, 22% smoked and 78% were non-smokers; this was statistically significant (p<0.05). Women with CIN 1 on subsequent cervical biopsies were equally distributed between smoker and non-smokers (Figure 4). This data suggests that a higher proportion of women who had CIN 2/3 on subsequent cervical biopsies were non-smokers.

Rates of teen pregnancy were high in our population of women with cervical HSIL; 71% had a history of a prior teen pregnancy. Another interesting observation was that of the 36 women who did not subsequently follow-up, 73% had a history of teen pregnancy. A history of teen pregnancy alone did not increase the rates of CIN 2/3 over CIN 1.

Table 1. Smoking, Teen Pregnancy and Cervical Pathology Distribution

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>CIN 1</th>
<th>CIN 2/3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teen Pregnancy/NS</td>
<td>35%</td>
<td>46%</td>
</tr>
<tr>
<td>Teen Pregnancy/S</td>
<td>39%</td>
<td>15%</td>
</tr>
<tr>
<td>No Teen Pregnancy/NS</td>
<td>9%</td>
<td>27%</td>
</tr>
<tr>
<td>No Teen Pregnancy/S</td>
<td>17%</td>
<td>12%</td>
</tr>
</tbody>
</table>

NS (non-smoker) and S (smoker)
As stated above, non-smoking women had higher rates of CIN 2/3. These women were further stratified to elucidate any confounding risk factors. We found that CIN 2/3 was most prevalent in women who were non-smokers with a history of at least one teen pregnancy (Table 1). Of the women with CIN 2/3, 46% were non-smokers with a history of teen pregnancy, 15% had a history of teen pregnancy and were smokers, 27% were non-smokers with no teen pregnancy and 12% had no history of teen pregnancy but were smokers. These differences were statistically significant at p<0.05 and warrants further investigation. In the CIN 1 group, women with a history of teen pregnancy regardless of smoking status constituted a higher proportion than the women with no history of teen pregnancy (Table 1).

**Discussion and Conclusions**

This small pilot study begins to examine if specific medical or lifestyle factors predict likelihood of CIN 2/3 following a HSIL Pap test result and affect the clearance of HPV. Several trends were identified and serve as a foundation for future research. We found that diabetes may be a potential risk factor for developing CIN 2/3. Three of the four women with diabetes who underwent colposcopy-directed biopsies had CIN 2/3. Women with extremes of weight (underweight and obese) have a two-fold greater chance of developing moderate to severe dysplasia following a HSIL Pap result. In our study, smoking, a known risk factor for cervical cancer, was not associated with CIN 2/3; non-smoking women had a two-fold greater chance of developing CIN 2/3. When the non-smoking women were further stratified, a history of teen pregnancy increased the risk of developing CIN 2/3 two-fold.

Although many of the results were found to be statistically significant (obesity, not smoking, non-smokers with history of teen pregnancy), this analysis must be taken with caution as to not overstate the results. One of the drawbacks of this study was the small number of patients in each category and formal statistical analysis is more accurately reported when study groups are larger. The high rate of loss to follow-up contributed to the low numbers in each category analyzed. We can only begin to follow trends that may be important.

In order to overcome this inherent limitation of our pilot study, we are reviewing charts of women with normal, LSIL, ASCUS, and ASCUS-H Pap test results spanning more years to obtain larger populations and increase statistical power. Additionally, we will also include patients from University Specialty
Clinics, our faculty’s private offices, in addition to the patients from Palmetto Health Women’s Center. The patients utilizing the private offices have a large proportion of minority patients because of the diverse population in SC, but not from different socioeconomic classes and access to health care. In contrast to the women who receive their care at Palmetto Health Women’s Center, the patients from our faculty offices tend to be highly educated and proactive about their health care; almost all have private health insurance. The addition of the patients from the faculty practices will increase the overall number of patients, including a substantial minority population to create better statistical power. Additionally, we will be able to assess if socioeconomics plays a role in developing cervical dysplasia.

One last conclusion from our pilot study, is that an extremely high number of women (27%) did not complete follow-up care after a HSIL Pap test result. A recent study of an urban population women (27%) did not complete follow-up. These women revealed that the vast majority were pregnant at the time of the abnormal Pap result and never had a colposcopy after their six week postpartum visit. It is unclear why these women never returned or were secondary to relocating, returning to a primary care physician for their care, and changing gynecologists. More likely, and more concerning, would be if the lack of follow-up is secondary to lack of health insurance. In SC, as is consistent with most states, women will qualify for Medicaid while pregnant, but coverage is terminated six weeks postpartum. Postpartum colposcopy is performed after the six weeks postpartum visit and is outside of this window. Studies are underway to further investigate why our patients are not appropriately completing follow-up. These issues are likely complex. Our plan is to devise a strategy involving a multidisciplinary approach with nursing staff, residents and attending physicians, and administration to ensure our patients get the most comprehensive care.

The pilot study has confirmed that both medical conditions and lifestyle practices may influence which women develop severe cervical dysplasia. Further studies are warranted to discern if these trends are present in larger populations of women. What is most interesting about these factors (diabetes, BMI, teen pregnancy), is that they are potentially modifiable through education and lifestyle changes. This research will hopefully help understand the racial disparities that exist in the progression of cervical dysplasia and cancer among AA and Hispanic women.

**Acknowledgements**

LBS receives partial salary support through the Centenary Fund at University of South Carolina. This study was supported in part by grant # SP20MD001770-04 from the National Center on Minority Health and Health Disparities. LBS is on Speakers Bureau for Qiagen; KEC and LPC are on the Merck’s Speakers Bureau.

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Willa Sullivan, a State Baptist Young Woman’s Auxiliary (YWA) member from Greenville, was scared when she received news that results from her annual Pap smear showed abnormal cells which could possibly be cancerous. She had to wait three months for a follow-up test, and during that time she lost her sister. “I just knew for sure I was going to be next, and my stress level was off the charts,” she said. “I was scared to death and did not want to go back to the doctor and receive the diagnosis.”

Ms. Sullivan is not alone in South Carolina where African-American women die at higher rates of cervical cancer than their white counterparts. Many women are often too afraid to return to their doctors for follow-up visits after getting abnormal Pap test results. Others are reluctant to schedule screenings and annual exams because they do not know what to expect, and the possibility of cervical cancer is so frightening.

That uncertainty and fear of the unknown lead many African-American women to call a familiar place—the Health Ministry Office of the State Baptist YWA of the Woman’s Baptist Education and Missionary Convention in South Carolina.

Affiliated with the Baptist Education and Missionary Convention, the largest African-American denomination in South Carolina, the State Baptist YWA was founded in 1953 to help minister to the vast needs of people in churches and communities. The health ministry, which is organized with regional coordinators in eight areas of the state, officially began in 2002. Four years later, the ministry office was fielding numerous calls from women with questions about cervical cancer, its symptoms, screenings and the human papillomavirus (HPV) vaccine.

The questions about cervical cancer required responses from experts that had up-to-date information and vast knowledge about the issue. The health ministry director recognized these questions could not go unanswered and therefore contacted research faculty at the University of South Carolina who work with the South Carolina Cancer Disparities Community Network (SCCDCN).

Together the State Baptist YWA and the researchers worked utilizing the elements of community-based participatory research to identify a way to answer the questions on a larger scale. In March 2007, they coordinated the first statewide community summit—A Call to Action: Preventing Cervical Cancer among African American Women.

The one-day summit in Columbia educated approximately 180 African-American women, men and teenagers from across the state about the specifics of cervical cancer. Participants: (1) heard national, state and local perspectives about cervical cancer and human papillomavirus vaccine; (2) identified successful strategies for prevention program implementation at the local and community levels; and (3) developed action plans to address the disease in their respective congregations and communities. In addition to the State Baptist YWA and the SCCDCN, other sponsors included the South Carolina Cancer Alliance, Carolina Community Based Health Supports Networks, Refuge Fellowship Ministries, the University of South Carolina Institute for Partnerships to Eliminate Health Disparities and its Center for Excellence in Cancer and HIV Research.

Since that time, the State Baptist YWA has continued its work with the SCCDCN to educate women and men about cervical cancer, HPV, and the impact among African-American women. YWA members have carried out the following actions at the local level:

- Hosting minister leadership forums,
- Organizing congregational cervical cancer educational sessions for members and community residents,
- Developing cervical cancer educational messages for church bulletin inserts (See Figure 1), and...
Receiving training to conduct research, delivering cervical cancer education and training others.

Research faculty and other health care professionals were key to the success of the cervical cancer educational sessions and training of the State Baptist YWA members. Training efforts focused on both cervical and breast cancer prevention and control.

The YWA members in Region One, which includes Anderson, Greenville, Oconee, Pickens and Spartanburg counties, launched South Carolina’s first Witness Project. This is a program where survivors known as witness role models “witness” or preach good news that cancer does not have to equal a death sentence. Two national Witness Project program trainers housed at the University of Arkansas for Medical Sciences trained 22 YWA members during an eight-hour session at the Greenville County Library. In April 2009, the YWA members in Region One trained an additional 16 young women in Region Two.

Additionally, Region Four, which includes Aiken, Allendale, Bamberg, Barnwell, Calhoun and Orangeburg counties, received funding from the Lowcountry affiliate of Susan G. Komen For the Cure to host train-the-trainer sessions, provide education, and encourage screening.

Not only have members trained to be trainers for the Witness Project, young women in the Pee Dee region were trained to conduct and implement research. Working with research faculty from the SCCDCN, young women from three participating churches in Region Six—which includes Chesterfield, Darlington, Dillon, Florence, Marion, and Marlboro counties—coordinated and conducted key informant interviews and focus groups as part of a research study examining opportunities for promoting information about the HPV vaccine in churches and acceptability and accessibility of the HPV vaccine within faith-based settings.

Because of its successful efforts to address cervical cancer, a State Baptist YWA team of lay advocates and witness role models have presented at various churches, conferences, and meetings. In April 2008, a Witness Project educational presentation was made to a National Cancer Institute/National Institute of Health project officer during a site visit with community representatives and research faculty. Also, a team of young women from Region One along with the health ministry director and research faculty from the SCCDCN presented a comprehensive overview of their breast and cervical cancer efforts at the American Cancer Society Annual Conference in August 2008. Results of these presentations included sharing useful information with other community and faith-based representatives and receiving ideas and plans for implementation.

Sustainability is always a question when funding is involved to support community initiatives. While some communities respond because of funding, most often respond because of their overall vision and program plan. Based upon the various initiatives to support breast and cervical cancer prevention and control, the State Baptist YWA is about ensuring its efforts continue to support the health ministry’s vision of Healthy Congregational Members Living in Healthy Communities Throughout the Lifespan.

Because Ms. Sullivan is an active YWA, she knew she had to face her fears about the possibility of cervical cancer. She knew...
early detection and treatment could save her life. So she went back to the doctor for her follow-up test. “One week later, they informed me that my cells were normal again. Praise God!” she said. “It has been stated that most women do not go back for the follow-up test, and we lose them to cancer. I cannot stress to you enough; please, please have an annual pap smear, and if there is an abnormal result, please, please follow-up.”

In African-American churches, there is an old familiar gospel song entitled, “When He Calls Me, I Will Answer.” This song speaks to being available to answer the call from on high to meet the needs of congregational members and others at the local, state and national levels through missionary efforts. Because of the State Baptist YWA’s efforts to address cervical cancer within in many congregations and communities, it is evident the call received has definitely been answered and continues to be answered.
The Upstate Witness Project: Addressing Breast and Cervical Cancer Disparities in African American Churches

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Dolores B. Scott, MEd  
Deloris G. Williams, RN, MSN, PhD

Background
African-Americans, (AAs) in the United States have higher cancer incidence overall when compared to whites; endure excess mortality as a result of reduced access to cancer screening, are more likely to be diagnosed at later stages, and more likely to receive less aggressive clinical care. African-American women in South Carolina (SC) suffer disproportionately from cancer disparities.

Breast cancer is the most commonly diagnosed cancer among women in SC, and SC ranks 19th in the nation for breast cancer mortality. Although incidence of breast cancer is higher among white women in SC, mortality rates are significantly higher among AA women in the state. The mortality rate observed in AA women is about 45% higher than in white women.

According to 2006 Behavioral Risk Factor Surveillance System (BRFSS) data, 87% of women aged 55-64 and 88% of females 65 and older in SC reported having a mammogram and clinical breast exam (CBE) within the past 3 years.

Seventeen percent of eligible AA women have not had a mammogram in the past two years compared with 22% of white women. Breast cancer screening mammography and CBE have been shown to decrease mortality.

SC ranks 8th in the nation for cervical cancer mortality. Cervical cancer mortality is almost 2.5 times higher in AA women than white women in SC. Further, AA women were 60% more likely to be diagnosed with cervical cancer than white women, and over twice as likely to die from the disease. These disparities exist, though more AA women were more likely to report having a Pap test in the past three years (92%) compared to white women (83%).

There are many potential contributing factors to the profound health disparities in SC. In SC, 16% of residents have no health insurance, and a higher percentage of AAs are uninsured. SC has more people with the lowest levels of literacy (Level 1 and 2) defined by the National Adult Literacy Survey when compared to the rest of the United States. Adults in these categories can perform simple tasks with text and documents, but display difficulty using certain reading, writing, and computational skills considered necessary for functioning in everyday life. In addition, SC is a rural state with 29% of residents living in rural areas and 78% of all counties designated as rural or very rural. AAs comprise >40% of the rural population in SC, which is the highest in the US.

The average per capita income of AAs in SC is $11,776 versus $22,095 for whites. Further, 35% of AAs have less than a high school degree.

The replication of the Witness Project (WP), which has been successful elsewhere, has the potential to help change the cancer disparities picture in SC. The WP has been implemented in 22 states at 33 sites across the country. The goals of the WP are to increase the number of women who practice regular cancer screening through Breast Self Exams (BSE), mammography, CBE and Pap testing. However, a majority of implementation sites have been large, urban settings. SC is a rural state. There are many AA churches in SC, some with large congregations. For AAs, the church is historically the central focal point of the community. The church, particularly in rural southern communities, is a major institution of social control, fellowship and education. Michielutte et al confirmed the importance of religion for social norms in the lives of AA women, and Ferraro and Koch found that generally, AAs may depend more on religion than whites do when there is a health crisis.

In 2003, Erwin et al. published data on the replication and dissemination of the WP in 21 sites. A logic model was developed to serve as a model for
replication. Quantitative and qualitative methods included a cadre of process and outcome measures to evaluate the effectiveness of the replication process. Key components and criteria of successful replication were established, and preliminary screening outcomes demonstrated a 43% increase in breast and cervical screening of previously un-screened or underscreened women aged 40 and older, following participation in a WP program. Process evaluation results indicated that three strategies are needed for replication: Establishment of Clear Objectives; Technical Assistance/Training; and Dual Champions.

### Methods

The Upstate Witness Project model (UWP) was implemented in Greenville, Spartanburg, Anderson, and Pickens counties, SC during 2008. The project team (members of the South Carolina Cancer Disparities Community Network (SCCDCN) and the State Baptist Young Woman’s Auxiliary (YWA)) in SC brought national trainers from Arkansas to the state during the training phase of this pilot project. The purpose of the pilot program was to recruit and train at least 20 Witnesses and (Lay Health Advisors) LHAs to provide breast and cervical cancer education information to reach at least 200 participants, with the ultimate goal of increasing the number of women who practice regular cancer screening through BSE, mammography, CBE and Pap testing. Witnesses (cancer survivors) and LHAs (non-cancer survivors) were recruited from participating counties through the YWA, the Best Chance Network (BCN) and American Cancer Society’s Reach to Recovery. WP information was shared in 14 church

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### Table 1. The Upstate Witness Project Witness Training Pre-Test/Post-Test (N=13)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>Std Dev</th>
<th>Std Error Mean</th>
<th>Lower</th>
<th>Upper</th>
<th>t</th>
<th>df</th>
<th>Sign (2-Tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>-2.23</td>
<td>1.16</td>
<td>.323</td>
<td>-2.93</td>
<td>-1.52</td>
<td>6.90</td>
<td>12</td>
<td>.000*</td>
<td></td>
</tr>
</tbody>
</table>

*significant at p < .05

*Note: 13 of 22 women trained completed both pre- and post-tests.

### Table 2. Demographic characteristics of Witness program participants (N=145)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 39 yrs</td>
<td>28</td>
<td>19.3</td>
</tr>
<tr>
<td>40-49</td>
<td>19</td>
<td>13.1</td>
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<tr>
<td>50-59</td>
<td>24</td>
<td>16.6</td>
</tr>
<tr>
<td>60-69</td>
<td>34</td>
<td>23.4</td>
</tr>
<tr>
<td>70-79</td>
<td>23</td>
<td>15.9</td>
</tr>
<tr>
<td>80-89</td>
<td>10</td>
<td>6.9</td>
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<tr>
<td>Missing</td>
<td>7</td>
<td>4.8</td>
</tr>
<tr>
<td>Ethnicity*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>116</td>
<td>80.0</td>
</tr>
<tr>
<td>White</td>
<td>25</td>
<td>17.2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>2.1</td>
</tr>
<tr>
<td>BSE in the past month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>106</td>
<td>73.1</td>
</tr>
<tr>
<td>No</td>
<td>35</td>
<td>24.1</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>CBE in past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>109</td>
<td>75.0</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>22.8</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>2.1</td>
</tr>
<tr>
<td>Mammogram in past 12 months*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>80</td>
<td>72.7</td>
</tr>
<tr>
<td>No</td>
<td>29</td>
<td>26.4</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>.9</td>
</tr>
<tr>
<td>Pelvic Exam in past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>95</td>
<td>65.5</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
<td>31.7</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>Pap Test in past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>98</td>
<td>67.6</td>
</tr>
<tr>
<td>No</td>
<td>44</td>
<td>30.3</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>2.1</td>
</tr>
</tbody>
</table>

*Excludes women under age 40 (n=110)
The Upstate Witness Project: Addressing Breast and Cervical Cancer Disparities in African American Churches

Table 3. Upstate Witness Pilot Program Outcomes*

<table>
<thead>
<tr>
<th>Outcome</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witnesses and LHAs recruited/trained</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Participants attending UWP presentations</td>
<td>422</td>
<td></td>
</tr>
<tr>
<td>Participants completing UWP registration forms</td>
<td>145</td>
<td></td>
</tr>
<tr>
<td>Participants requesting assistance</td>
<td>56</td>
<td>38.6%</td>
</tr>
<tr>
<td>Participants referred for breast and cervical screening</td>
<td>34</td>
<td>23%</td>
</tr>
</tbody>
</table>

*January, 2008-December, 2008

Due to the lack of available space, the full table of data is not included here. Please refer to the original source for the complete table.

Results

A total of 22 Witnesses and LHAs were trained. However, only 13 Witnesses and LHAs completed both pre- and post-tests. The results from these pre-/post-assessments are shown in Table 1. Trained Witnesses and LHAs showed a 19% increase in knowledge of breast cancer at completion of the training. The mean knowledge score increased from 9.5 (sd=1.45) on the pretest to 11.8 (sd=.83) on the post-test. The difference between the two means is statistically significant at the .05 level (t= 6.90 ; df=12). Note that only breast cancer knowledge was addressed on the pre- and post-tests.

Table 2 shows the demographic and cancer screening characteristics of the 145 participants who completed the program evaluation. About 53% of participants were between 40-69 years of age and the majority were AA (80%). In total, 24.1% of participants had not performed a BSE in the past month; 55% did not perform BSE at recommended intervals; 22.8% had not obtained a CBE, mammogram (26.4%), pelvic exam (32%), or Pap test (30%) in the past 12 months.

Of those completing registration forms (n=145), 38% of women requested some type of assistance. To date, 34 women (23%) have been referred for breast and cervical screening services. Table 3 shows the primary program outcomes.

Bivariate analyses examined the relationship between age and cancer screening behaviors. No significant relationships were found between age and BSE, or CBEs, pelvic exams or Pap tests. A significant relationship (p<0.5) was found between age and having a mammogram in the past 12 months (Chi-square= 5.896, df=5). Women aged 60-69 were more likely to have had a mammogram in the past 12 months than all other age groups (data not shown). In addition, there was a relationship between age and how often women had a Pap test (Chi-square=36.02, df=10) (Table 4).

Bivariate analyses also examined the relationship between ethnicity and cancer screening behaviors. When examining the relationship between ethnicity and cervical cancer screening, ethnicity was significantly related to how often women had a pelvic exam (Chi-square= 23.77, df=5). Women aged 60-69 were more likely to have had a pelvic exam during the past year. There was a relationship between age and how often women had a Pap test (Chi-square=36.02, df=10) (Table 4).

Conclusions

This study demonstrated that the WP model may be an appropriate method for
reaching women through AA churches in SC. The evaluation outcomes of the pilot project are promising. Witnesses and LHAs showed an increase in knowledge of breast cancer at completion of the training. This provides evidence of the program’s effectiveness in improving knowledge of breast cancer screening among those trained to present.

The purpose of the pilot program was to recruit and train at least 20 Witnesses and LHAs to provide breast and cervical cancer education information to reach at least 200 participants, with the ultimate goal of increasing the number of women who practice regular cancer screening through BSE, mammography, CBE and Pap testing. The UWP far exceeded the goals of the pilot program, reaching 422 participants, with 145 completing registration forms. One factor contributing to this success is that initially Witnesses and LHAs were each asked to conduct one to three presentations in their local churches. Because several of the Witnesses attended churches in the same region and presented in pairs, many met this goal early in the program. Many of the 22 Witnesses and LHAs have continued to volunteer after their commitment had been met.

It is important to note that a UWP informational presentation was made at the State Baptist’s YWA Annual Convention to 500 participants who did not complete program registration forms. There was an overwhelmingly positive response, but for a variety of reasons, believed by the project team to be due to factors such as time, literacy and trust. Some participants chose to sign the program sign-in sheet, but not the program registration form. The project team will work more with Witnesses and LHAs in the future to stress the importance of collecting program registration forms from all participants.

The majority of participants were between 40 and 69 years of age, so the program appears to be reaching its target population of women ages 40 and older for breast cancer and 18 and older for cervical cancer.

A majority of UWP participants did not perform BSE at recommended intervals: performed either daily, weekly, or yearly. The percentage of women reporting not having a CBE or mammogram in the past 12 months is slightly lower than the state data of (38.4%) and Erwin et al.’s finding of 36.7% non-adherence. The percentage of participants reporting not having a pelvic exam in the past 12 months is slightly higher than AA women in SC (30%) and similar to Erwin et al. finding of 36.4%. The percentage of participants reporting no Pap test usage in the past 12 months is similar to 36% of AA women in SC and Erwin et al. finding of 37.5%. The fact that the ‘ever’ test for pelvic exam was not significant while ‘frequency’ of testing was notable. Routine cancer screening is crucial to detecting cancer in its earliest stages and increasing survival rates. These data would lead one to believe that there is no disparity in screening rates. However, it is important to note that only 60% of participants responded to the question regarding frequency of having a pelvic exam or Pap test in the past year. A se-
Table 5. Relationship among ethnicity and cancer screening behaviors

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Pelvic exam</th>
<th>( \chi^2 ) (df)</th>
<th>How often get Pelvic exam</th>
<th>( \chi^2 ) (df)</th>
<th>Pap Test</th>
<th>( \chi^2 ) (df)</th>
<th>How often get Pap test</th>
<th>( \chi^2 ) (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>1 yr</td>
<td>&gt;1yr</td>
<td>Yes</td>
<td>No</td>
<td>1 yr</td>
<td>&gt;1yr</td>
</tr>
<tr>
<td>African-American</td>
<td>75</td>
<td>37</td>
<td>1.23(2)</td>
<td>48</td>
<td>1</td>
<td>4.93(1)*</td>
<td>79</td>
<td>35</td>
</tr>
<tr>
<td>Caucasian</td>
<td>19</td>
<td>6</td>
<td>9</td>
<td>2</td>
<td>18</td>
<td>6</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

a=results based on participants completing these items on program registration form. *significant at \( p<.05 \)

lection bias for ‘preferred answers’ may have impacted the study results. It is also possible that some women did not distinguish between a “pelvic exam” and a “Pap test”. Future efforts will include defining each term separately and stressing the importance of participants completing the entire survey.

A significant relationship was found between age and having a mammogram in the past 12 months. Women aged 60-69 were more likely to have had a mammogram in the past 12 months than all other age groups. In addition, women aged 60-69 were more likely to have had a pelvic exam and have had a Pap test during the past year. These findings are similar to Erwin et al’s 17 findings. It is believed that these findings are due to the fact that many women in this group are eligible for Medicare and due to recent layoffs in the Upstate community, many younger women in this group may be uninsured or underinsured and not accessing services.

When examining the relationship between ethnicity and cervical cancer screening, ethnicity was significantly related to how often women had a pelvic exam, with AA women were more likely to report having a pelvic test within one year. It is believed that these findings may be skewed due to the fact that 80% of the participants were AA.

Implications of the Work for the Public Health Community

This study demonstrated that the WP model may be an appropriate model for reaching women through AA churches in SC with the goal of increasing the number of women who practice regular cancer screening through BSE, mammography, CBE and Pap testing. The evaluation outcomes of the pilot project are promising. Since the sample lacked a control group and only cross sectional data were obtained, we cannot determine with certainty the full impact of the UWP. Second, as noted by Erwin, et al 29 there may be some bias in responses toward more socially acceptable answers. As the UWP expands past the pilot phase, the team hopes to collect baseline and follow-up data on all participants.

The YWA were instrumental in providing access to and recruiting women in the Upstate community. Rural AA churches provide a minimal amount of structure with which to work. 30 For the majority of presentations, Witnesses and LHAs contacted church leaders (ministers or other YWA members) directly and requested a presentation. Some presentations were made as part of an existing program (a women’s missionary health day or women’s missionary tea) and others were free-standing programs. By utilizing members of the YWA in this region, Witnesses were provided an entrance into local churches and viewed by participants as trustworthy. After several initial presentations, the success of the UWP was spread via word-of-mouth, and churches began to contact the Witnesses for presentations. This snowball effect was evidence of the participation and responsiveness of the churches to this type of culturally sensitive, community-based effort. Thirty-eight (38.6%) percent of women requested some type of assistance through the UWP. Every effort was made to contact these participants within two weeks of the presentation.

Three phone call attempts were made for each participant. Initially, these phone calls were made by the project coordinator at Clemson University, and later by two trained LHAs. The LHAs had more success in reaching women and referring them to screening. When a woman was identified as needing screening services and met the appropriate criteria, they were referred to the BCN outreach worker who scheduled their appointment. To date, 34 women (23%) have been referred for breast and cervical screening services.

The BCN, SC’s state program funded through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides free breast and cervical screening services to women between the ages of 40-64 who meet the income guidelines. However, it appears that many women are still not accessing these services. It is our hope the UWP will serve to augment the efforts reduce cancer disparities by increasing screening in women who may need it most (in rural and minority communities).

The project team is working with the BCN to develop a future follow-up and
tracking system for women identified through the UWP who are unscreened and in need of services. As Erwin, et al have noted, “designing an innovative health education program for special populations is a time- and labor-intensive process.” The UWP had clear objectives; utilized dual champions; provided technical assistance and training; and involved AA churches and groups such as the YWA and BCN from the beginning and can have a lasting impact in reducing breast and cervical cancer disparities in underserved communities. As noted previously, “in supporting the cultural values of the survivors and their communities, the project took on a life, vitality and synergism of its own that proved greater than the individual parts.”

References
25. Brandt H, Modayil M, Daguisse V, et


Background
Cancer is a leading cause of morbidity and mortality among Hispanics in the United States (US). At both the national and regional levels, Hispanic women experience higher incidence of cervical cancer compared to Blacks and non-Hispanic Whites. In 2005, the age adjusted invasive cervical cancer incidence rates for Hispanics in the South Atlantic US was 11.5 per 100,000 compared to 10.0 per 100,000 for Blacks and 8.1 per 100,000 for non-Hispanic Whites. The death rate from cervical cancer is 50% higher among Hispanic women than among non-Hispanic White women. Underutilization of screening services and poor adherence to diagnostic follow-up are believed to contribute to the increased mortality among Hispanic women. In addition, the majority of South Carolina’s Latinos are Mexican immigrants (62%), a sub-population with a high prevalence of human papillomavirus (HPV) infections associated with an increased risk of cervical cancer. Most of the current population data on cervical cancer among US Latinos is reflective of the populations in large metropolitan areas and border areas with historically high concentrations of Hispanics. However, the higher rates of cervical cancer in the South Atlantic region may be predictive of expected rates in South Carolina (SC), where access to health care among burgeoning Hispanic communities of primarily recent immigrants is compounded by the very limited number of Spanish-speaking health professionals in the region.

The Hispanic population is the largest and fastest-growing minority group in SC and the nation. By 2000, the increasing awareness of the magnitude of the recent influx of Hispanics in SC was confirmed through census data. At the urging of community leaders, the governor charged the SC Commission for Minority Affairs (CMA) to facilitate discussions with the local Latino community to identify ways to better meet the needs of this growing population. The CMA established a Hispanic/Latino Ad Hoc Committee with the charge of identifying barriers to service delivery among LEP Hispanics in five key areas: 1) Education, 2) Health, 3) Public Safety, 4) Human Rights, and 5) Immigration, Transportation, and Fraud. The health subcommittee activities involved the mobilization of over 50 individuals from statewide health care agencies and community-based organizations. The group engaged in discussions and participatory processes over a
six-month period, with the aim of identifying and prioritizing the current SC Hispanic health issues, problems and concerns. The group identified five top priority issues: language and communication barriers; lack of cultural competency on the part of both providers and those seeking services; access to care barriers (e.g., cost, insurance, transportation); lack of data for health planning and surveillance; and immigration and social issues (e.g., lack of documentation, discrimination). In the resulting report to the governor, the health subcommittee noted that these priority issues cut across the wide range of potential health and illness concerns among the SC Latino population, such as diabetes, hypertension, cancer, heart disease, prenatal care, occupational health, and communicable diseases. There was clear consensus that these overarching systemic issues must be addressed in order to ensure the provision of culturally and linguistically appropriate quality health care.

After completing the Hispanic Health component of the CMA report to the governor, participants remained motivated and empowered to maintain the momentum generated from the assessment of Hispanic health needs and resources, priority-setting and formulation of policy recommendations, and decided not to disband, but to regroup and form a permanent entity. The result was the formation of the SC Hispanic/Latino Health Coalition (hereafter referred to as the Coalition) with the express mission of advocating for access to quality health care for Latinos. In 2002, the Coalition became the first federally-recognized non-profit 501c3 organization in the state to focus exclusively on Hispanic health issues. The result was the establishment of a permanent SC Hispanic/Latino Health Coalition (hereafter referred to as the Coalition), a response to community pressures to develop and sustain the newly formed Coalition, a response to community needs and priorities. In CBPR, community participation has direct influence on the development, planning, and implementation of research. Effective CBPR initiatives are characterized by engagement of members of the various communities of interest in the research processes, that include identifying and prioritizing the research questions, having ownership of the information gathered, disseminating the results to their own constituencies, and continuing to benefit from the research experience after the funding period ends.

Potential benefits to both researchers and communities of interest include increased effectiveness through engagement of community wisdom in planning and implementing research, enhanced community trust, and improved sustainability through the transfer of skills and resources to community individuals and institutions. Rather than entering the community with a predefined research agenda and timeline, the role of the academic researcher in CBPR is to be a willing research partner, open to building long-term relationships based on mutual trust and respect.

In the case of the PCP, we initiated steps to building trust and relationships through our collective engagement in developing and sustaining the newly formed Coalition, a response to community and stakeholder-identified needs and priorities. The inclusive and participatory nature of the project, which included members of the SC Latino community, health care providers, public health professionals, Latino outreach workers, and academic researchers, was in line with CBPR principles. Through the Coalition, the PCP brought together local representatives from the American Cancer Society, Cancer Information Service, Clemson University, Hispanic Assistance and Bilingual Access Project (HABLA), Pal-

### Implementing a Community-Based Participatory Research (CBPR)

With the establishment of the Coalition, the groundwork was laid for the first formal community partnership initiative to address Hispanic health issues. The SC Breast and Cervical Cancer Early Detection Program/Best Chance Network (BCN), a Coalition member, identified the need to increase the involvement of uninsured age- and income-eligible Latinas in their free breast and cervical cancer screening program. To this end, the BCN invited other Coalition members to participate in the strategic planning process for renewal of a grant from the Centers for Disease Control and Prevention. A new BCN priority was to increase the percentage of women screened who had not received a Pap test in five or more years.

Concurrently, Redes en Acción: National Hispanic/Latino Cancer Research Network, funded through the National Cancer Institute, issued a call for proposals focusing on Hispanic cancer-related issues. The initiative was driven by the national focus on the elimination of racial/ethnic health disparities and concomitant acknowledgement by leading behavioral and social scientists that successful interventions involve communities as partners in the design, implementation, and evaluation of interventions. The Coalition’s mission was to improve access to quality health care for Hispanics. The BCN had programs and services that it wanted to make available to Latinas; and University of South Carolina (USC) researchers were interested in developing effective and sustainable interventions to eliminate health disparities. The confluence of these various initiatives set the stage for the development of the PCP, a collaborative CBPR proposal involving the Coalition, BCN, and USC, funded through a Redes en Acción grant.

CBPR is an action-oriented approach to research in which community representation is based on both structural (e.g., geographic, physical, organizational) and functional (e.g., social groups based on language, race, ethnicity, faith) communities of interest. In CBPR, community participation has direct influence on the development, planning, and implementation of research.
The Partnership for Cancer Prevention: Addressing Access to Cervical Cancer Screening Among Latinas in South Carolina

Our next step was the collective identification of the two-fold aims of PCP research: to further our understanding of Latina’s attitudes and behaviors around cervical cancer prevention and early detection; and to determine the extent to which local cervical cancer prevention programs were able to provide culturally and linguistically appropriate services. The dual focus of the project required different data collection methods (i.e., focus groups and surveys) with very different populations (i.e., community-dwelling Latina immigrants, health care providers and support personnel). The dual focus of the project required different data collection methods (i.e., focus groups and surveys) with very different populations (i.e., community-dwelling Latina immigrants, health care providers and support personnel). The dual focus of the project required different data collection methods (i.e., focus groups and surveys) with very different populations (i.e., community-dwelling Latina immigrants, health care providers and support personnel).

Exploring Latinas’ Attitudes and Behaviors: Design and Methods

To answer our questions about Latinas’ attitudes and behaviors around cervical cancer prevention and detection, we conducted focus groups in two different regions of the state (Midlands and Upstate). PCP members from our community of interest (e.g., Latina community organizers and representatives from Hispanic Outreach) were integral to the success of the planning and implementation of the focus groups. These Latina PCP members were responsible for identifying and recruiting participants, identifying a suitable community location, arranging transportation for participants, providing assistance before and during the focus group sessions, and participating in the analysis of the resulting qualitative data. Because this was an exploratory study, inclusion criteria were quite broad (e.g., Spanish-speaking, women 18 years or older that self-identified as Hispanic or Latino).

In both the Midlands and Upstate we recruited participants for two groups and held two sessions with each group, for a total of 8 focus group sessions. The decision to conduct two sessions with each group was in response to concerns raised by PCP members who recognized the cultural inappropriateness of addressing potentially sensitive issues with Latinas with whom we had not developed a level of rapport and trust. Therefore, in the first session we began by exploring the broader issues of health care access, knowledge of health care services, barriers to services, and awareness of cancer and perceptions about personal risks for cancer. In the second session (usually a week later), we addressed more sensitive issues including cervical cancer, family planning, prevention of sexually transmitted infections, and communication about women’s health issues with a partner or spouse.

When participants arrived at the site, PCP members greeted them, provided refreshments, and assisted in completing informed consent and demographic forms. Trained bilingual PCP members facilitated the audio-taped focus groups in Spanish and also served as note-takers. Each focus group lasted approximately 2 hours. At the conclusion of the first session, participants were compensated with a $10 gift card and a $15 gift card and Spanish educational material on breast and cervical cancer at conclusion of the second session. Bilingual professionals from a PCP member organization transcribed the tapes in Spanish. PCP member organizations that provided research support for recruitment and transcription received compensation from grant funds.

We invited PCP members who were fluent in Spanish to participate in the qualitative analysis of transcript data, a process facilitated by one of the academic partners, an experienced qualitative researcher. A few participants had some prior experience in qualitative methods, but others had none. Each member of the analysis team read the transcripts...
individually, looking for salient themes, particularly in relation to the women’s knowledge of cervical cancer, cultural myths and beliefs in regards to cancer risks, personal experiences and perceptions of screening and treatment, and awareness of personal cervical cancer risks. We then met collectively to compare our individual findings and identify those salient themes for which there was mutual consensus.

**Exploring Latinas’ Attitudes and Behaviors: Findings**
The sample consisted of 38 Latina residents, with a mean age of 31.85±12.31 years (see Table 1). The majority were married (73%), born outside the US (93%), mostly in Mexico, had less than a high school education (61%), and had total family incomes below $1,100 per month (68%). More than half of the women (58.6%) had received a Pap test in the last year; 33% received a Pap test more than one year ago, and 8% had never received a Pap test.

Very few of the women had any ideas regarding cervical cancer etiology or treatment. These women also echoed attitudes noted in other research, such as fatalistic beliefs about cancer (“If they tell me I have it, I’ll die”). They demonstrated very little knowledge about cancer risks, identifying tubal ligation, oral contraceptives, and untreated vaginal infections as potential cervical cancer risks. Other identified causes of cancer included environmental contaminants (electric magnetic fields, sun exposure, nuclear waste), heredity, and cigarettes. Most participants had some degree of familiarity with the Pap test procedure, but there was no evidence that they fully understood the purpose of the test. Women reported initiating cervical cancer screening upon marriage; most concurred screening should be repeated every six months to one year. The main reasons for having a Pap test was “peace of mind” and caring for oneself for the sake of the family. Barriers to cervical cancer screening included fear of the “unknown,” “unsterilized instruments,” “HIV,” “pain,” and embarrassment of being “seen or touched down there.” Inability to choose, communicate with, or relate to their health care providers (“you

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**Table 1. Characteristics of Focus Group Participants (N=38)**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years (Mean ± SD)</strong></td>
<td>31.9 ± 12.3</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married, living with spouse or partner</td>
<td>71.0</td>
</tr>
<tr>
<td>Married, not living with spouse</td>
<td>15.8</td>
</tr>
<tr>
<td>Not married</td>
<td>10.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Place of Birth</strong></td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>84.2</td>
</tr>
<tr>
<td>United States</td>
<td>7.9</td>
</tr>
<tr>
<td>Other</td>
<td>7.9</td>
</tr>
<tr>
<td><strong>Highest Degree Earned</strong></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>40.5</td>
</tr>
<tr>
<td>Middle School</td>
<td>18.9</td>
</tr>
<tr>
<td>High School</td>
<td>10.8</td>
</tr>
<tr>
<td>Vocational Degree or Certificate</td>
<td>16.2</td>
</tr>
<tr>
<td>College/University</td>
<td>13.5</td>
</tr>
<tr>
<td><strong>Country of Education</strong></td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>77.8</td>
</tr>
<tr>
<td>U.S.</td>
<td>13.9</td>
</tr>
<tr>
<td>Other</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>65.8</td>
</tr>
<tr>
<td>Employed</td>
<td>23.7</td>
</tr>
<tr>
<td>Student</td>
<td>5.3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5.3</td>
</tr>
<tr>
<td><strong>Monthly Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>less than $700 per month</td>
<td>47.2</td>
</tr>
<tr>
<td>$700-$1,099 per month</td>
<td>16.7</td>
</tr>
<tr>
<td>$1,100-$1,499 per month</td>
<td>22.2</td>
</tr>
<tr>
<td>$1,500 per month</td>
<td>13.9</td>
</tr>
<tr>
<td><strong>Adults living in household, (Mean ± SD)</strong></td>
<td>3.03±1.32</td>
</tr>
<tr>
<td><strong>Children &lt; 18 living in household, (Mean ± SD)</strong></td>
<td>2.03±1.36</td>
</tr>
<tr>
<td><strong>Personal History of Cervical Cancer (% yes)</strong></td>
<td>2.6</td>
</tr>
<tr>
<td>Last Pap Test</td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>55.3</td>
</tr>
<tr>
<td>≥ 1 year and &lt; 2 years</td>
<td>31.6</td>
</tr>
<tr>
<td>≥ 2 years</td>
<td>5.3</td>
</tr>
<tr>
<td>Never</td>
<td>7.9</td>
</tr>
</tbody>
</table>

*percentage may not equal 100% due to rounding*
get who you get”) contributed to stress, anxiety, and decreased utilization of cervical cancer screening services.

The most common reason for seeking formal health care among these women was for prenatal health care services. Many women had only had a Pap test because they had become pregnant; most reported not actively seeking family planning services or other preventive reproductive health care services prior to marriage or pregnancy. Not surprisingly, these Latinas did not understand the US health care system, with its eligibility and insurance criteria and different types of providers and settings. Other than prenatal care, preventive care was not a priority health care need among these women. If they sought care it was for acute illnesses or emergencies. In addition to language and communication barriers, significant barriers to health care included costs, lack of child care or transportation, and no source of primary care.

A commonly voiced expectation was the identification of family members (e.g., mothers, specifically, but also sisters, grandmothers, aunts, and others) as individuals these Latinas trusted, confided in, and from whom they sought advice and health information. Although participants reported having consulted their mothers and other family members regarding many issues, there were certain health issues, such as sexuality, family planning, and life-threatening illness (e.g., cancer) that were rarely addressed within these intimate family and social networks. These Latinas cited “doctors” as a good source of information for advice regarding cancer. However, they seldom went to the doctor, and if and when they did, did not actively ask questions or request information or referrals for preventive services. Shame, embarrassment, language barriers, and fear of “bad news” all contributed to this behavior. Although they indicated doctors would be a good source of advice, they preferred bilingual/bicultural outreach workers with whom they could communicate better and on the same level. These were primarily bilingual/bicultural program staff with strong community ties and established relationships with “gatekeepers” within the formal health system. However, the most common source of health information was lay contacts such as friends, family, neighbors, or trusted sources (e.g., church, work-site). These informal contacts provided assistance in making phone calls, scheduling appointments, providing transportation, and informal interpreter services.

**Access to Cultural and Linguistically Appropriate Services: Design and Methods**

Our second research aim was to assess the cultural and linguistic appropriateness of the existing services providing cervical cancer screening to Latinas, and the level of knowledge and experiences of health practitioners and support personnel in contact with Latina clients through these cancer screening services. To this end, we developed two surveys, one for practitioners and the other for support personnel. To facilitate this process, PCP academic researchers created a compendium of cultural competency assessments, based primarily on the work of Goode and Tirado, which was shared with other members. Collectively, we then identified and selected items for each survey. We designed the practitioner survey for those who provide direct patient services (e.g., nurses, physicians, social workers, health educators, and nutritionists) and the support personnel survey for administrative and clinical support staff (e.g., nursing and medical assistants, receptionists, and clerical staff).

PCP members representing the state health department, BCN, and a community cancer screening program volunteered to conduct the survey in their clinical sites and recruited 14 breast and cervical cancer screening providers in Fairfield, Lexington, Newberry, and Richland counties to participate. Each organizational member was responsible for obtaining approval for and coordinating data collection for their respective provider sites. To facilitate data collection and minimize breach of confidentiality, the surveys were anonymous, but color-coded by site. Respondents who completed and returned the anonymous surveys were assumed to consent to participate in the research. PCP representatives from each of the participating sites took responsibility for oversight of the research process. This included providing clinic staff with a brief description of the PCP research project; explanation of the voluntary nature of participation in the survey; and instructions for completing the paper and pencil survey, placing it in a sealed envelope, and returning it to a designated location. At each site, a PCP representative gathered the surveys and forwarded them to project staff. Each site that participated in the survey received Spanish-language educational materials on breast and cervical cancer and cultural competency resources provided by the Cancer Information Service, a PCP member.

Survey respondents were asked to assess availability and importance of language services and resources, perceptions of Latina clients’ service needs, Latina client profile, and respondent characteristics. Respondents were presented with a list of services and resources, including: eight items on bilingual staffing (e.g., nurses, doctors, health educators, social workers, nutritionists, administrators, receptionists, and clerical staff), six items on Spanish-language resources (i.e., interpreters, clinic forms, signs and notices, educational materials, 24-hour hotline, and printed material), and three items on documentation of language preference (English-language proficiency and literacy level on clinic records). For each service/resource listed, respondents reported how often it was provided at their clinic, from 1 = never to 5 = always, and...
how important they thought it was, from 1 = Unimportant to 5 = Very Important. Seven open-ended items asked respondents about their perception of the health and social problems facing Latinas, why Latinas come to their clinic, and changes they thought were needed at the clinic to improve care and cultural competency for Latinas at the personal and organizational level. Respondents provided information on the number of Latina clients served per month, percent female, age, and immigrant status. Respondents provided personal demographic information on gender, race, education, Spanish-language capacity, and past participation in cultural competency training.

All data received from participating sites were entered, managed and analyzed using the Statistical Package for the Social Sciences (SPSS), Version 16 (Chicago, Ill.) Means and standard deviations were calculated and simple descriptive and univariate statistics were first examined followed by bivariate analyses to assess differences between providers and staff on key variables of interest. Levene’s two-tailed t-test for unequal variances was used to account for the heterogeneous variances observed in the sample.27 Cronbach’s alpha coefficients for Likert-type scales were calculated. Scores ranged from 0.713 to 0.963, indicating very good reliability.

### Access to Cultural and Linguistically Appropriate Services: Findings

We distributed 152 surveys to four county health departments, one community cancer screening program for the indigent, and nine private family practice providers with current BCN contracts with the SC Department of Health and Environmental Control. We received 76 completed surveys (50% response rate); 60% were completed by practitioners and the remaining 40% were completed by support personnel (Table 2). The majority (78.3%) of practitioner respondents were nurses. The sample was composed of participants from county health departments (47%), private providers linked to the BCN (42%), and a community health center (11%). Respondents were primarily female (96%) and White (78%). The low level of linguistic competency of the sample was indicated by the fact that 70% reported being uncomfortable communicating with Latina clients in Spanish.

Table 3 presents provider and staff re-
ports on the availability of language resources and services at their clinics and their perceived importance of these resources and services. There were no significant differences between providers and staff on their perception of the availability of language resources and services. Both providers and staff perceived that language support services were provided most often followed by documentation of language and literacy. Respondents reported that bilingual staff was mostly “not at all” available. With respect to the value or importance of language resources and services, providers rated language support services as significantly more important than staff ($t = -2.72$, d.f. = 37, $p < .05$). The primary concern of providers and staff was addressing the language needs of Hispanic clients, including a need for Spanish educational materials, forms and signage, and access to on-site interpreters (Table 4). Although there was a general concern about the availability of language assistance services, there was less recognition of other aspects of cultural competency. In general, responses suggested a lack of awareness about the local Hispanic community. For example, nearly 50% of the respondents were not able to answer questions regarding the country of origin or immigration status of the local Hispanic community or of the Hispanic clients at their agencies; 47.9% reported not having received any formal training specifically focused on serving Latina clients. The majority (55%) reported having daily or weekly contact with Hispanic clients. However, less than 25% were “often” or “always” satisfied with their ability to provide culturally appropriate services.

### Table 3. Comparison of Provider Perceptions of Importance and Availability of Language Resources and Services

<table>
<thead>
<tr>
<th>Resources and Services</th>
<th>How Often Provided</th>
<th>How Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bilingual Staff</td>
<td>$1.66 \pm 0.49$</td>
<td>$3.84 \pm 0.67$</td>
</tr>
<tr>
<td>Document Language &amp; Literacy</td>
<td>$2.38 \pm 0.98$</td>
<td>$4.10 \pm 0.56$</td>
</tr>
<tr>
<td>Language Support Services</td>
<td>$3.18 \pm 0.80$</td>
<td>$4.35 \pm 0.47$</td>
</tr>
</tbody>
</table>

* $t = -2.72$, d.f. = 37, $p < .05$ Levene’s $t$ Statistic for Equality of Means Separate Variance formula

### Table 4. Provider Perceptions of Latina Health Issues

<table>
<thead>
<tr>
<th>Health problems among Latinas (N=49)</th>
<th>Percent (%)</th>
<th>Clinic needs to improve care (N=50)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obesity</td>
<td>20%</td>
<td>On-site interpreters</td>
<td>33%</td>
</tr>
<tr>
<td>Sexually Transmitted Infections</td>
<td>18%</td>
<td>Spanish classes for staff</td>
<td>27%</td>
</tr>
<tr>
<td>Birth Control</td>
<td>16%</td>
<td>Signs &amp; educational materials in Spanish</td>
<td>17%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>16%</td>
<td>English classes for Latino clients</td>
<td>11%</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>14%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate or no regular medical care</td>
<td>12%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor diet</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No prenatal care</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* open-ended responses listed were identified by at least 10% of respondents, so they won’t add up to 100%
Translation and dissemination of linguistically appropriate services. The most common reasons attributed to clinic attendance by Hispanic clients were related to cost; 35% (n=24) identified “sliding fees for payment” or “free medical care” as the reason that Latinas came to their clinics. The most pressing health problems among Hispanic clients were reproductive health issues including pregnancy (22%) and sexually transmitted infections (18%); obesity was also commonly reported (20%). With regard to social issues, language barriers (68%), financial concerns such as “poverty,” cost of health care services, being uninsured (41%), and transportation (30%) were most common.

Translating Research Evidence to Practice

After completing the data analyses for both the qualitative and quantitative components of the research, we held a day-long PCP meeting to discuss the results and identify and prioritize strategies for future actions. As a result of this process, we were more acutely aware of Latinas’ misinformation about cancer etiology, lack of a prevention orientation, and their distrust and lack of understanding of the US health care system. This knowledge helped us understand more fully the barriers to care that Latinas encounter. Our findings indicated that practitioners’ main concerns revolved around language access; other aspects of culturally appropriate care, such as identification and documentation of language preference or ability and bilingual staffing, were considered less important. To address Latinas’ cervical cancer knowledge gaps and mistrust and misunderstanding of the US health care system, we recommended the development and dissemination of linguistically and culturally appropriate information about availability, accessibility, costs, and benefits of cancer screening services to Latinas through the use of lay informants. At the organizational level, our primary recommendations for action included the provision of trained interpreters or Spanish-speaking staff and cultural education and training for providers and staff aimed at improving relationships and trust with Latina patients.

Following the completion of this CBPR project in 2003, individual PCP member organizations have continued to translate the evidence and recommendations into educational, programmatic, organizational, and research initiatives. Specifically, the Coalition developed and disseminated a cultural competency training program for health and social service providers throughout the state; the BCN committed resources to recruit, hire, and train bilingual Latina outreach workers and subsequently hired a full-time Latina BCN outreach worker for the Upstate region; community health centers and health departments made Spanish-language forms and materials available at their clinics; and USC researchers conducted community-based intervention research aimed at improving Hispanic immigrants’ ability to access and navigate the US health care system. PCP members continue to use their collective experience and findings from the assessments to inform program planning within their respective breast and cervical cancer control efforts. Most recently, in 2007-2009, the PCP leveraged its skills and resources to obtain funding through the Coalition, American Cancer Society, and the SC Cancer Alliance to develop and implement the Iniciativa Latina contra el Cáncer (Latina Cancer Prevention and Early Detection Initiative), a coordinated, culturally-relevant, community-engaged intervention involving media, outreach and education provided by trained lay Latina health educators, and enhanced provision of culturally and linguistically appropriate quality cancer control services.

Over the past eight years, the PCP has remained committed to leveraging resources and addressing barriers to cervical cancer screening among this newly emerging population of Latinas in SC. The partnership has resulted in recommendations for action and research to improve health care access. PCP members also have experienced the benefits of collaborative partnerships by recruiting culturally-appropriate personnel to enhance the BCN’s program reach of vulnerable Latina women and improve their utilization of local cervical cancer screening services.

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Introduction
“South Carolina (SC) had the third fastest growing Hispanic population in the United States (US) between 2000 and 2006 and Hispanic women in the US die more often of cervical cancer compared to other racial and ethnic groups.” As a result, healthcare providers face numerous challenges as they adapt their services to the diverse needs of this fast-growing immigrant population. To be effective, cervical cancer prevention efforts must be culturally and language appropriate for Hispanic women. Lay health educators, known in Spanish as promotoras, play an important role in reaching out to the community and relaying health information to increase awareness of and promote cervical cancer screening.

Who are the promotoras?
In October of 2008, the South Carolina Hispanic/Latino Health Coalition (SCHLHC) identified and recruited four Latinas in Richland and Lexington Counties to be trained as promotoras for a breast and cervical cancer community education project, the Iniciativa Latina contra el Cáncer (Latina Cancer Initiative). The women were already engaged in a variety of community outreach projects. Lidia Navarrete is the director of the Good Samaritan Clinic, a free clinic with a strong emphasis on providing a Hispanic-friendly healthcare environment. Yadira Calvo is an outreach worker for a local Lutheran church who also worked as an English-as-a-second-language (ESL) instructor at Columbia Farms in West Columbia. Minerva Flores is the Parent-Teacher Association president of Gilbert Primary School and works as an interpreter in ESL classes for Spanish-speaking adults at the Lexington Church of Christ. She and Lorena Ruiz are both well known in the Lifelong Learning Center, where many young Hispanic adults attend ESL classes.

Promotora roles in cervical cancer education and screening
The promotora’s roles include providing community cancer health educational sessions, assisting Latinas with access to screening services, and conducting follow-up with women participating in the project. As part of the Iniciativa Latina, each promotora recruited 7 to 12 Hispanic women from their communities to participate in breast and cervical cancer educational sessions. Utilizing the South Carolina Cancer Alliance (SCCA) Spanish language edition of the Cancer Education Guide they are able to provide a personal referral for each participant to a specific cancer screening service based on American Cancer Society guidelines, the participant’s insurance status, and county of residence. The promotoras also follow up with each participant to verify appointments and screening received.

Many of the women the promotoras work with are relatively young, lack health insurance, and are limitedly proficient in English. They refer women under 40 who lack health insurance and have low family incomes to the public health department in their respective county or to the Palmetto Health Cancer Health Initiative program (PHCHI), where they are able to obtain free Pap tests. The promotoras also work with women over 40 who qualify for and are referred to Best Chance Network (BCN). In addition to the Spanish language Cancer Education Guide, the promotoras also share health education materials with the women in the Hispanic community. They distribute Su Salud newsletters published by the SCHLHC at clinics, tiendas (Hispanic stores), and even to women they met in Wal-Mart.

Barriers to screening services
During follow-up with participants, the promotoras are able to identify barriers to accessing screening, including language, lack of telephone and/or transportation, inflexible work schedules, perceived discrimination, geographic mobility, and miscommunication with the clinics. Yadira found some women are slow in calling to make their screening appointments. “I tell them to call today. Not next week, not next month. Many of them are scared that someone is going to answer the phone very rapidly in English and they won’t know how to respond. Sometimes the person answering the phone will say, “we don’t speak Spanish” and hang up, even when interpreters are available at the facility” says Yadira. Even when the receptionist says, “wait a moment”
and puts the caller on hold while she goes to find an interpreter, women tend to hang up because they don’t understand that they should wait for the interpreter to come on the line, because she didn’t say it in Spanish.” While this is the case, Yadira recognizes these are some of the many reasons and barriers these women face and why they do not call for their appointments.

For those women who do succeed in making appointments, further issues often arise. When Yadira followed up with two sisters who were scheduled for Pap tests on the same day, “They were called and told that their appointments had been cancelled because of the weather. The person on the phone said they would be called back for a new appointment, but that never happened.” Another problem is that many of the women do not have reliable telephone service. For instance, one woman referred to BCN gave the number of the telephone that she and her husband share. When the BCN coordinator tried to call to set an appointment, she found that the husband works on two- to three-week contracts in different cities and by the time he returned home to his wife, he had forgotten to give her the message about the BCN appointment.

The lack of reliable telephone communication and the propensity to be isolated can negatively affect these Hispanic women beyond the initial step of getting an appointment. Lorena worked with one Latina who thought she had cervical cancer. “I couldn’t call her to find out what was really going on because she didn’t have a phone. What I do know is that she wouldn’t eat, she wouldn’t leave her house, she wouldn’t do anything around her house. She was very depressed.” When Lorena saw her weeks later, she reminded her that abnormal Pap test results do not necessarily mean she has cancer. “The woman went back to the clinic and found out that everything was okay. She’s doing so much better now. But you know, when people find out they have cancer, they still think that means they’re going to die. So, that’s what we try to do, we try to tell them that they have a chance to live. They just have to take control.”

The promotoras have encountered a few cases of women who participated in the educational sessions but have subsequently returned to their home countries. Others reported making appointments but having to cancel due to their full work schedules. During an interview with Lidia Navarrete at the Good Samaritan Clinic, a young girl walked in, very upset, because she had gone to her appointment thinking that the Pap test would be free of charge, only to find out that the clinic was charging $35. She was sure it was discrimination and left without seeing the doctor because she didn’t have the money. Lidia reflected afterward, “I would still refer them there, because that’s still a good price and a good service, but I want to make sure I’m giving these women the right information. It’s certainly a shock when you’ve been told that something is free and then you show up and they say you have to pay. These places know us; the women take our cards with them when they go to their appointments. The clinics need to tell us when they change a policy so that we don’t give out wrong information.”

**Positive experiences and hope for future efforts**

Despite the many barriers facing Hispanic women seeking breast and cervical cancer screening services, the promotoras reported successes, as well. Lorena and Minerva have had women in each of their sessions that already see a private doctor for annual Pap
tests. According to Minerva, “Some of the women had already gone to get their annual Pap test even a few days before they found out about the education sessions I was holding. They already have their appointments for the next year!” Also, upon follow-up, Minerva said, “The women are so happy when I call them to see if they’ve made their appointments. I was so emotional after this one day that I called a bunch of the women and they were all so happy. It made me see how my work with the Latina Initiative is affecting these women and giving them something positive in their lives.”

The promotoras reflected positively on their work in the community and expressed hope that the systemic glitches can be resolved so that the women they work with won’t be turned away from services they need. Minerva and Lorena have a two-page list of women who want to attend a future cancer educational session. These stories are evidence that women in the local Hispanic community are eager to learn; it is up to providers and the system to make sure we can reduce the existing barriers and disparities experienced by this population.

References
Participatory Evaluation of Community-Based HPV and Cervical Cancer Prevention and Control Efforts

Sarah Griffin, PhD
Saundra H. Glover, PhD, MBA
Andrea W. Williams, MEd
Heather M. Brandt, PhD

Introduction
This paper describes efforts to evaluate community actions to develop community-based interventions to reduce the incidence of cervical cancer and the mortality associated with cervical cancer in one South Carolina county. The overall incidence rate of cervical cancer in this community is 17.1 cases per 100,000 women and the mortality rate is 2.6 deaths per 100,000. However, the mortality rate is almost twice as high (4.2) among African American (AA) women.

Cervical cancer is largely preventable with regular screening (e.g., Pap test and human papilloma virus (HPV) DNA test) and adherence to recommended follow-up care. Unfortunately, many people remain unaware of the link between some types of HPV and cervical cancer. Studies in the United States and the United Kingdom have found low levels of HPV knowledge regarding risk factors, sexual transmission, disease management, cancer risk, or even basic awareness among young adults, adolescents, and adult women.

In recognition of cervical cancer disparities and the opportunities for addressing precursors to behavior, the Community Partnership and Outreach Core (CPOC) of the University of South Carolina (USC) and Claflin University Center of Excellence (COE) in Cancer and HIV Research is a community-based participatory initiative to develop and implement culturally and linguistically appropriate public health programs, resources, and services to eliminate HIV and HPV related health disparities. The specific aims of the CPOC are:

1. To develop, assemble, and engage community leadership in the form of a Community Advisory Group (CAG) to identify strategies for meeting the preventive and treatment needs of the community specific to HIV/AIDS and HPV/cervical cancer;
2. To provide technical assistance to the community for planning, designing, adapting, implementing, and evaluating community programs, services, and resources;
3. To serve as a resource for the community;
4. To develop and implement programs, services, and resources to reduce HIV/AIDS and HPV and cervical cancer health disparities within the community;
5. To assist with community capacity development opportunities;
6. To evaluate the community-based participatory research (CBPR) approach impact on the community and health outcomes during the project period.

The CAG is a crucial component of the CPOC. It guides the efforts of the CPOC, engages the community in an assessment process, oversees a mini-grant process to establish programs in the community; and participates in training events to build HPV knowledge and capacity. CAG members are adult, minority (AA) residents of the intended county who have an expressed interest in HIV/AIDS and/or HPV and cervical cancer. Through the CAG, the CPOC uses a community-based participatory approach to address the specific aims. Thus, a participatory evaluation approach is used to evaluate the work of the CPOC. This approach was chosen because of its emphasis on involving stakeholders in designing and implementing the evaluation and in the use of evaluation findings.

The CPOC evaluation is a multistep, non-linear, process, adapted from Fuerstein (1988) and Springett in Minkler and Wallerstein (2003). Evaluation steps (Table 1) are revisited over the course of the project and reinitialized each time the project begins a new phase.

Having members of the project (CAG members) involved in data collection and analysis may be perceived as a potential risk to evaluation objectivity. However, given the participatory nature of this project and the importance placed on learning through the evaluative process, it was decided that steps (such as evaluation methods training, collecting, and analyzing data in teams) would be taken to ensure objectivity, while still including CAG members in these activities. Participatory evaluation recognizes...
the value of having those that are most familiar with the programs and services included in interpreting the data. It provides a context for the findings often missing in traditional evaluations. By having the CAG fully engaged in all evaluation activities, the process has also helped to build evaluation capacity within the community.

**Methods**

The CPOC used a mixed-methods evaluation design that employed several qualitative and quantitative methods. Data collection methods in the CPOC evaluation were influenced by the evaluation objectives and the abilities of the evaluation coordination team. The evaluation team, comprised of CPOC investigators, a consultant, CPOC staff, and CAG members. At least half of the team must be comprised of CAG members.

The annual survey assessing CAG functioning was adapted from previous instruments measuring group partnership. The central characteristics measured through this survey include: shared leadership, participation, and communication; number of participants engaged in the activity; and the CAG members’ role in the activity. Data from the logs were entered into Excel each month. Evaluation team members reviewed the results each month and an activity report highlighting the frequency and type of activities was shared with the CAG during the monthly meetings.

**Community Impacts**

The CPOC and CAG conducted key informant interviews, focus groups, and surveys with community members (not included in the CAG) as part of an initial community-wide assessment to establish a baseline level of: awareness, knowledge, perceptions of services and capacity (e.g., leadership, community participation, community resources, advocacy, planning, community involvement, communication, and creativity). This was a helpful tool in monitoring CAG functioning and engaging CAG members in discussions and problem solving, which is consistent with a participatory evaluation approach.

Prior to administering the survey each year the evaluation team reviewed the survey for appropriateness. The annual CAG functioning survey was completed by CAG members at the beginning of one meeting each year. Members that were not present during the meeting were asked to complete it and bring it with them to the next meeting. After the data were collected they were entered into SPSS and mean scores were calculated for each survey item. Once compiled, data were shared with the evaluation team. The evaluation team discussed and collectively interpreted the findings. The results were then shared with the CAG.

CAG member participation in HIV, HPV, or cervical cancer community activities were captured through a log that the members completed and returned to the evaluation team each month. The log assessed the activity type, topic and location; number of participants engaged in the activity; and the CAG members’ role in the activity. Data from the logs were entered into Excel each month. Evaluation team members reviewed the results each month and an activity report highlighting the frequency and type of activities was shared with the CAG during the monthly meetings.

**Table 1. CPOC Evaluation Steps**

<table>
<thead>
<tr>
<th>Step</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1: Select an evaluation coordination team</td>
<td>The evaluation coordination team is comprised of CPOC investigators, a consultant, CPOC staff, and CAG members. At least half of the team must be comprised of CAG members.</td>
</tr>
<tr>
<td>Step 2: Decide on evaluation objectives</td>
<td>The evaluation team develops evaluation objectives based on: assessment findings, CPOC specific aims, and CAG needs and capacities.</td>
</tr>
<tr>
<td>Step 3: Choose methods for attaining evaluation objectives</td>
<td>Qualitative and quantitative methods are used to assess CAG functioning (annual survey), CAG efforts (CAG member logs and CAG sponsored event surveys), community members’ knowledge of HPV, HPV services, and perceptions of HPV risk (focus groups and surveys).</td>
</tr>
<tr>
<td>Step 4: Report evaluation plan to CAG</td>
<td>The evaluation team shared the evaluation plan with the CAG, received feedback, made adjustments to the plan and had the plan endorsed by the CPOC and CAG.</td>
</tr>
<tr>
<td>Step 5: Test methods, collect and analyze evaluation data</td>
<td>Data is collected by the evaluation coordination team and analyzed by the team along with the investigators. It is recognized that having members of the project involved in data collection and analysis is perceived to potentially impact objectivity.</td>
</tr>
<tr>
<td>Step 6: Share findings and make decisions</td>
<td>Findings are shared in written, oral, visual, and verbal formats to accommodate a wide variety of capabilities and preferences for how information is learned.</td>
</tr>
</tbody>
</table>
### Table 2. CAG Functioning

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Listen to ideas of all members</td>
<td>3.3</td>
<td>3.17</td>
<td>3.41</td>
</tr>
<tr>
<td>Give you a chance to share your ideas and views</td>
<td>3.29</td>
<td>3.06</td>
<td>3.44</td>
</tr>
<tr>
<td>Make people feel welcome and wanted as part of the CAG</td>
<td>3.57</td>
<td>3.11</td>
<td>3.28</td>
</tr>
<tr>
<td>Create a safe place to share views and ideas</td>
<td>3.33</td>
<td>3.31</td>
<td>3.28</td>
</tr>
<tr>
<td>Bring together people with an interest in HIV/AIDS and HPV/cervical cancer</td>
<td>3.62</td>
<td>3.28</td>
<td>3.61</td>
</tr>
<tr>
<td>Help new members understand the project</td>
<td>3.15</td>
<td>2.78</td>
<td>2.89</td>
</tr>
<tr>
<td>Use the storymaps to tell the story of disparities</td>
<td>2.95</td>
<td>3.13</td>
<td>3.29</td>
</tr>
<tr>
<td>Celebrate progress</td>
<td>3.30</td>
<td>3.06</td>
<td>3.35</td>
</tr>
<tr>
<td>Share information about CAG activities (for example, there is not a lot of “insider” information that only a few in the CAG know)</td>
<td>3.16</td>
<td>3.06</td>
<td>3.11</td>
</tr>
<tr>
<td>Share information about upcoming events and activities to all CAG members</td>
<td>3.48</td>
<td>3.00</td>
<td>3.33</td>
</tr>
<tr>
<td>Share information about HIV/AIDS and/or HPV/cervical cancer work in Orangeburg County</td>
<td>3.33</td>
<td>3.06</td>
<td>3.39</td>
</tr>
<tr>
<td>Accomplish what we should during the meeting</td>
<td>3.10</td>
<td>2.67</td>
<td>3.28</td>
</tr>
<tr>
<td>Accomplish what we should outside the meeting time</td>
<td>2.94</td>
<td>2.65</td>
<td>3.12</td>
</tr>
<tr>
<td>Have an agreed upon method of leadership</td>
<td>3.14</td>
<td>2.78</td>
<td>3.31</td>
</tr>
<tr>
<td>Have an agreed upon process for making decisions</td>
<td>3.10</td>
<td>3.85</td>
<td>3.06</td>
</tr>
<tr>
<td>Share responsibility and workload so that work is accomplished together</td>
<td>3.05</td>
<td>2.75</td>
<td>3.18</td>
</tr>
<tr>
<td>Build a clear mission of CAG/COE</td>
<td>3.11</td>
<td>2.59</td>
<td>3.00</td>
</tr>
<tr>
<td>Resolve conflict within group</td>
<td>3.0</td>
<td>2.76</td>
<td>3.18</td>
</tr>
<tr>
<td>There is a shared vision for the CAG</td>
<td>3.15</td>
<td>3.00</td>
<td>3.11</td>
</tr>
<tr>
<td>The CAG has a set of goals and strategies for creating change in Orangeburg County</td>
<td>3.05</td>
<td>2.88</td>
<td>3.06</td>
</tr>
<tr>
<td>I can see how my personal vision fits the CAG vision</td>
<td>2.95</td>
<td>3.00</td>
<td>3.22</td>
</tr>
<tr>
<td>CAG works with a broad range of groups in Orangeburg County</td>
<td>2.86</td>
<td>2.72</td>
<td>3.22</td>
</tr>
<tr>
<td>CAG members share responsibility and workload so that work is collaborative.</td>
<td>3.00</td>
<td>2.71</td>
<td>3.00</td>
</tr>
<tr>
<td>CAG decisions are made together with everyone on the CAG having the opportunity to participate.</td>
<td>3.00</td>
<td>3.00</td>
<td>3.06</td>
</tr>
<tr>
<td>As a group we are able to resolve conflict in order to reach a decision.</td>
<td>3.00</td>
<td>2.89</td>
<td>3.11</td>
</tr>
<tr>
<td>Decision making power is shared and not in the hands of a few.</td>
<td>3.05</td>
<td>2.94</td>
<td>2.94</td>
</tr>
<tr>
<td>Leadership in the CAG is shared.</td>
<td>3.10</td>
<td>2.71</td>
<td>3.11</td>
</tr>
<tr>
<td>All CAG members are heard and respected.</td>
<td>3.11</td>
<td>3.06</td>
<td>3.17</td>
</tr>
<tr>
<td>Capacities and skills of CAG members are recognized and used with the CAG process.</td>
<td>2.94</td>
<td>2.82</td>
<td>3.11</td>
</tr>
<tr>
<td>Information about upcoming CAG events and activities are shared with all members.</td>
<td>3.25</td>
<td>2.88</td>
<td>3.44</td>
</tr>
<tr>
<td>The communication activities of the CAG enhance communication with the larger community.</td>
<td>2.94</td>
<td>2.76</td>
<td>3.06</td>
</tr>
<tr>
<td>CAG members have relationships to gain support of local organizations.</td>
<td>3.00</td>
<td>2.88</td>
<td>3.17</td>
</tr>
<tr>
<td>Successful activities of the CAG are incorporated into ongoing work of local organizations.</td>
<td>2.90</td>
<td>3.00</td>
<td>3.11</td>
</tr>
</tbody>
</table>

Note: Table reflects means responses for how much each respondent agreed with each statement on a scale of one (strongly disagree) to four (strongly agree)
programs, and views regarding stigmatization of those with HIV/AIDS and HPV/cervical cancer. This information was used to help guide the work of the CPOC and CAG. Key informants and focus group participants were asked to complete a short survey as part of the interview or group discussion. The evaluation coordination team included a small number of closed-ended questions regarding access to screening and other services pertaining to HIV/AIDS and HPV and cervical cancer.

Key informant and focus group participants were identified via a multi-step process. The first step involved dividing the county into 4 distinct regions. CAG members from each region identified local key informants (individuals) and key organizations in several different categories (e.g., government, business, education, faith-based, civic, social, and grassroots groups). Once the regional lists of individuals and organizations were compiled the individuals were contacted about participating in an interview and the organizations were contacted about hosting a focus group with their members. Key informants and organizations were also asked to identify additional key individuals and organizations to add to the list for each region. This process continued until a minimum of two individuals and two organizations were identified for each category.

CAG members interested in assisting with the key informant interviews and focus groups participated in a four hour (over two days) training on: qualitative data expectations; interviewer and moderator tasks; interviewer and moderator skills; attributes of effective interviewers and moderators; recognizing and limiting actions that may introduce bias; protecting confidentiality; the interview and focus group guide; and note taking skills. Interviews were conducted by the CPOC investigative team members with CAG members assisting as note takers. Focus groups were moderated by trained CPOC staff and CAG members. Interviews and focus groups were audiotaped then transcribed.

A five person team (two investigators, one CPOC staff member, one student and one consultant) reviewed a subset of transcripts to develop the initial set of analysis codes. Analysis of qualitative data (using the constant comparison method) began as soon as audiotaped interviews were transcribed verbatim and reviewed for quality control purposes.\textsuperscript{35} 36 In keeping with principles of qualitative analysis, the analysis team did not impose preconceived coding schemes onto the data. Coding was based on both a thematic and pattern analysis.\textsuperscript{37} Themes were defined in terms of their meaning to the informant and/or focus

### Table 3. Key Informant Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>31 (100)</td>
</tr>
<tr>
<td><strong>Age (years)</strong> Mean (S.D.) – 47.6 (12.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13 (41.9)</td>
</tr>
<tr>
<td>Female</td>
<td>18 (58.1)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>28 (90.3)</td>
</tr>
<tr>
<td>White</td>
<td>3 (9.7)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>1 (3.2)</td>
</tr>
<tr>
<td>Some college</td>
<td>8 (25.8)</td>
</tr>
<tr>
<td>College degree</td>
<td>22 (71.0)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>18 (58.0)</td>
</tr>
<tr>
<td>Single</td>
<td>7 (22.6)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (19.4)</td>
</tr>
<tr>
<td><strong>Insurance</strong></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>22 (71.0)</td>
</tr>
<tr>
<td>Medicaid/Medicare</td>
<td>7 (22.6)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (6.4)</td>
</tr>
<tr>
<td><strong>Knowledge about the cause of cervical cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>13 (41.9)</td>
</tr>
<tr>
<td>Incorrect</td>
<td>18 (58.1)</td>
</tr>
<tr>
<td><strong>Knowledge about the route of HIV transmission</strong></td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>26 (83.9)</td>
</tr>
<tr>
<td>Incorrect</td>
<td>5 (16.1)</td>
</tr>
<tr>
<td><strong>Heard about HPV</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25 (80.7)</td>
</tr>
<tr>
<td>No</td>
<td>6 (19.3)</td>
</tr>
<tr>
<td><strong>Heard about HPV vaccine</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26 (83.9)</td>
</tr>
<tr>
<td>No</td>
<td>5 (16.1)</td>
</tr>
<tr>
<td><strong>Known a woman who has had cervical cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (58.1)</td>
</tr>
<tr>
<td>No</td>
<td>13 (41.9)</td>
</tr>
<tr>
<td><strong>Known anyone who has HIV</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30 (96.8)</td>
</tr>
<tr>
<td>No</td>
<td>1 (3.2)</td>
</tr>
</tbody>
</table>
group participant(s). Codes were identified, used to code transcripts, and then compared across interviewees and focus groups for presence or absence of specific themes. Pattern analysis, by contrast, was a more “etic” interpretation of text data that was grouped by specific codes. The meaning was identified by the analysis team based on behavioral and community theory, knowledge of HPV and cervical cancer, and geographic patterns in the community. Once analysis was completed, findings were shared with CAG members for additional interpretation and meaning.

Results

CAG Functioning and Efforts

The results of the annual CAG survey (Table 2) revealed a highly functioning CAG. Most item scores averaged 3.0 or higher (on a scale of 1 to 4 with 4 being the value representing highest functioning or most positive impressions). Results revealed a CAG that struggled with a few issues in the second year of the project, but quickly regrouped and began functioning at a high level again in year 3. The highest average scores were found in measures assessing the CAG’s success in bringing people together with a shared interest in HIV/AIDS and HPV and cervical cancer and providing a forum to share ideas and information. Additionally, the survey revealed that CAG members almost doubled the amount of time that they committed to CAG related activities from 3.2 hours per month during the first year of the project to 6.2 hours per month in the third year. The CAG member logs revealed that CAG members reported participating in 69 HIV/AIDS or HPV and cervical cancer community events over a seventeen month period. Additionally, CAG members had a coordinating or organizing role in an overwhelming majority of these events.

Community Impacts

Findings from the community surveys (Tables 3, 4 and 5), as well as 31 key informant interviews and 11 focus groups conducted during the summer of 2007, reflected several differences in the types of information that community residents perceived as most important to include in education and awareness programs focused on HPV and cervical cancer. Results also illuminated key differences and similarities in health issues, HPV needs, and resources. Finally, these findings prompted several key suggestions for methods to effectively reach community residents with prevention programs. Participants identified a number of health issues for rural communities. Interestingly, higher priority was assigned to social

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total = 37 (100)</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Mean (S.D.) – 21.1 (2.2)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10 (27.8)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (72.2)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>35 (94.6)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>9 (24.3)</td>
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<tr>
<td>Some college</td>
<td>26 (70.3)</td>
</tr>
<tr>
<td>College degree</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>Marital Status</td>
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<tr>
<td>Married</td>
<td>4 (11.1)</td>
</tr>
<tr>
<td>Single</td>
<td>32 (88.9)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>17 (47.2)</td>
</tr>
<tr>
<td>Medicaid/Medicare</td>
<td>7 (19.4)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (5.6)</td>
</tr>
<tr>
<td>None</td>
<td>10 (27.8)</td>
</tr>
<tr>
<td>Knowledge about the cause of cervical cancer</td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>24 (66.7)</td>
</tr>
<tr>
<td>Incorrect</td>
<td>12 (33.3)</td>
</tr>
<tr>
<td>Knowledge about the route of HIV transmission</td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>36 (100.0)</td>
</tr>
<tr>
<td>Heard about HPV</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28 (80.0)</td>
</tr>
<tr>
<td>No</td>
<td>7 (20.0)</td>
</tr>
<tr>
<td>Heard about HPV vaccine</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15 (42.9)</td>
</tr>
<tr>
<td>No</td>
<td>20 (57.1)</td>
</tr>
<tr>
<td>Known a woman who has had cervical cancer</td>
<td></td>
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<td>Yes</td>
<td>9 (25.0)</td>
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<td>27 (75.0)</td>
</tr>
<tr>
<td>Known anyone who has HIV</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (50.0)</td>
</tr>
<tr>
<td>No</td>
<td>18 (50.0)</td>
</tr>
</tbody>
</table>
and economic concerns such as gangs, drug use, violence, poor education, and poverty as opposed to concentrating on specific illnesses or diseases. Also emphasized was the need for educational programs that keep children in schools (i.e., reducing drop-out rates). However, residents recognized and discussed how these issues are interconnected.

With reference to access to health care, residents identified several key factors associated with access. Issues included travel distance required to reach some forms of care and the need for transportation assistance and/or the need for more services offered within their local communities. They also talked about the cost of health care, especially for people without health insurance.

Participants had many questions about HPV and cervical cancer. Many of these questions confirmed a need to focus on increasing the level and accuracy of knowledge about HPV along with efforts to increase awareness of HPV. Questions from participants include:

- Is HPV a new form of HIV?
- How is HPV transmitted?
- How are you tested to find out if you have HPV?
- How effective is the HPV vaccine?
- When are girls vaccinated for HPV?
- What is (should be) the role of schools, families, friends in sex education?
- What is the relationship between HPV and cervical cancer?

Participants had several ideas on how to help community members be healthier (in general). They discussed programs that addressed lifestyle behaviors such as exercise and eating. They also talked about the need for educational programs to raise awareness of a variety of health issues. They recognized the need for programs addressing youth needs related to youth risk behaviors and steps regarding how to prevent and/or treat these health conditions. Finally, participants discussed the broader need for more health care in the community. Within this conversation, the need for increased access to health screenings (locally, within community) came up as topic of particular interest.

Participants provided several suggestions in response to specific initiatives which could be possible in their community regarding HPV and cervical cancer. Considerable discussion focused on the need for education/awareness programs and how these programs should occur in a wide variety of locations with a wide

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total = 85 (100)</td>
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<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Mean (S.D.) – 21.1 (2.2)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (25.9)</td>
</tr>
<tr>
<td>Female</td>
<td>63 (74.1)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>83 (97.6)</td>
</tr>
<tr>
<td>White</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>42 (49.4)</td>
</tr>
<tr>
<td>Some college</td>
<td>19 (22.4)</td>
</tr>
<tr>
<td>College degree</td>
<td>24 (28.2)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>33 (38.8)</td>
</tr>
<tr>
<td>Single</td>
<td>37 (43.5)</td>
</tr>
<tr>
<td>Other</td>
<td>15 (17.7)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>47 (56.6)</td>
</tr>
<tr>
<td>Medicaid/Medicare</td>
<td>19 (22.9)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (3.6)</td>
</tr>
<tr>
<td>None</td>
<td>14 (16.9)</td>
</tr>
<tr>
<td>Knowledge about the cause of cervical cancer</td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>28 (33.7)</td>
</tr>
<tr>
<td>Incorrect</td>
<td>55 (66.3)</td>
</tr>
<tr>
<td>Knowledge about the route of HIV transmission</td>
<td></td>
</tr>
<tr>
<td>Correct</td>
<td>67 (79.8)</td>
</tr>
<tr>
<td>Incorrect</td>
<td>17 (20.2)</td>
</tr>
<tr>
<td>Heard about HPV</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>50 (58.8)</td>
</tr>
<tr>
<td>No</td>
<td>35 (41.2)</td>
</tr>
<tr>
<td>Heard about HPV vaccine</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>29 (34.9)</td>
</tr>
<tr>
<td>No</td>
<td>54 (65.1)</td>
</tr>
<tr>
<td>Known a woman who has had cervical cancer</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34 (40.5)</td>
</tr>
<tr>
<td>No</td>
<td>50 (59.5)</td>
</tr>
<tr>
<td>Known anyone who has HIV</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>59 (69.4)</td>
</tr>
<tr>
<td>No</td>
<td>26 (30.6)</td>
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</table>
variety of people within the community. The participants also talked about the need for funding for educational programs and programs to assist people in need. Lastly, participants talked about the HPV vaccine and discussed their own uncertainties about the vaccine and the general lack of knowledge about the vaccine in terms of its availability, cost, effectiveness, etc.

Finally, participants suggested several methods that they thought would be effective for reaching the community regarding HPV and cervical cancer programs. Most of the methods that they identified represented interpersonal “grassroots” efforts such as working with local organizations, collaborating with the health ministries of churches and other faith-based institutions, and one-on-one conversations with community residents, as opposed to the use of print or electronic media.

Participants who were asked specific questions about HPV illustrated the need for more accurate information related to cervical cancer and HPV. Many incorrect responses (Tables 3, 4 and 5) were offered to questions such as: (1) How is HPV transmitted? (2) How are you tested to find out if you find it? (3) What is the HPV vaccine? (4) What is cervical cancer? (5) What causes cervical cancer? (6) When are girls vaccinated for HPV?

Discussion
Decisions about methodologies for conducting an evaluation of a community program require consideration of several factors such as: how evaluation data will be used; the evaluation questions to be answered; and the need or desire to build community evaluation capacity.28 A participatory approach was used for this project because of the emphasis on continually sharing the evaluation findings to help guide and shape the community efforts and because of the desire to build evaluation capacity among the CAG. Findings from this evaluation were shared in written, oral, visual, and verbal formats to accommodate a wide variety of capabilities and preferences for how information is learned. All findings were first shared with the evaluation team for interpretation and decision-making regarding the best format for sharing with the CAG and the community. The goal was to create an open forum that generated discussion on how to improve community partnership and outreach efforts. This approach was based on evidence that suggests learning about your progress and critically reflecting on successes and challenges can be a difficult process for many. For example, in the second year of the CAG the evaluation data identified a decrease in functioning. This was difficult to hear, especially given the hard work that the members had put into the CAG. However, the CAG members used this information to help reorganize, develop by-laws and invest in the development of a strong member-leadership structure to guide the group. This type of reflection requires a safe environment, honesty, and skill on behalf of the facilitator to minimize defensive behavior.29

The CAG, through its program planning subcommittee, used the findings of the Center’s evaluation process to guide their actions and efforts to support education and awareness programs, link people to resources, and address gaps in current services and programs. For example, findings from the interviews and focus groups indicating concerns regarding youth risky behavior helped shape a focus on developing HPV and cervical cancer awareness and education programs for youth and young adults and helped shape the delivery methods for awareness building and educational information.

Conclusion
Cervical cancer disparities are influenced by complex social and behavioral factors. A community-based ecological approach to address individual (knowledge, attitude) interpersonal (family and peer influences), and community/policy (access to preventive service, access to care) is required to eliminate this disparity.30 Through a participatory evaluation approach community members have the opportunity to use the evaluation findings to continually improve their efforts and build their evaluation skills. While this approach has many strengths (e.g., inclusive, findings raise awareness, shared control, builds skills), it has several inherent challenges. Participatory evaluations are at a great risk for bias in the findings.31 It is crucial that the evaluation team takes measures (e.g., training evaluation team members; using mixed method designs) to minimize bias and ensure reliability and validity of the findings. Additionally, participatory evaluation approaches are typically more time-consuming and the role of an evaluation team comprised of professional evaluators and engaged community members is crucial.32

Implications for Public Health
The participatory evaluation framework used in this study provided an example of functioning and impact data that can be used in evaluation of community-based participatory research approaches. It also shows how the evaluation can serve to create a climate of reflection and self and group assessment so that findings are used to establish a baseline, monitor efforts, and assess functioning. Through this process data are used to continually improve the group processes, and assess community impacts. This approach that used data systematically to inform HPV and cervical cancer practice and engage community members in HPV and cervical cancer discussions is in keeping with the key components of evidence based public health.33

Acknowledgements
The authors would like to gratefully acknowledge the following for their significant contribution to the CAG evaluation
efforts: the evaluation subcommittee (Sandra Bush, Maleiah Clayton, Daysell Chavis (current chair), Geraldine Day, Aisha Graham, Tessie Hayward, Jessica Hook, Shirley James, Pat Kelly, Anthony Lawson (past chair), Mario Murray, Crystal Myers, JoJo Rhines, Arlene Rustin, Tiffany Stewart, Yolanda Sumpter, John Ureda, Dr.PH, Thomasina White (past chair), and Stephanie Williams); current and past CAG members; the CPOC staff (Tiffany Stewart, LMSW and Karen Clinton) and investigative team (Gloria McCutcheon, PhD Tasha Louis Nance, EdD, Gemma Geslani, and Karen Clinton) and investigative team (Gloria McCutcheon, PhD Tasha Louis Nance, EdD, Gemma Geslani, and Patricia Motes, PhD); Chinelo Ogbuanu, MD, PhD, and Patricia Motes, PhD); Chinelo Ogbuanu, MD, PhD, MPH, and the Center for Excellence in HIV and Cancer Research.

References


One of the first steps to adhering to recommendations for cervical cancer screening, understanding the importance of follow-up care and treatment of abnormal screening results, and making decisions about the HPV vaccine is to have accurate and understandable information. Awareness and knowledge of an issue are precursors to initiating necessary action and following through. Health care providers are an excellent and trusted resource for information on cervical cancer and HPV. Sometimes, patients desire more information or simply to have what has been shared with them by a health care provider confirmed and available to review after an office visit. In those instances, having accurate and understandable information available in the office or easily accessible is helpful. Most of the following resources are available at no charge and can be accessed by health care providers and the public. Many of the materials are also available in Spanish, and some materials are available in specific formats for American Indians, African Americans, other racial and ethnic groups, parents, and youth. Two helpful phone numbers are the American Cancer Society at 1-800-ACS-2345 (227-2345) and the Cancer Information Service of the National Cancer Institute at 1-800-4-CANCER (422-6237). In addition to public health education and patient education, sometimes health care providers require resources to stay abreast of the latest health and medical developments. Resources for health care providers are also included.

**Resources for the Public:**

**Centers for Disease Control and Prevention (CDC)**
Division of STD Prevention
http://www.cdc.gov/std
1-800-CDC-INFO (1-800-232-4636)
National HPV and Cervical Cancer Prevention Hotline: 919-361-4848

**CDC: Making Sense of your Pap and HPV Test Results**
(Spanish version: http://www.cdc.gov/std/Hpv/pap/HPV_Patient_Spanish_booklet.pdf)

**CDC: Genital HPV Infection Fact Sheet**
Printable version available at: http://www.cdc.gov/std/healthcomm/fact_sheets.htm
(Spanish version: http://www.cdc.gov/STD/Spanish/STDFact-HPV-s.htm)

**CDC: HPV and Men Fact Sheet**
Printable version available at: http://www.cdc.gov/std/healthcomm/fact_sheets.htm
(Spanish version: http://www.cdc.gov/std/Spanish/STDFact-HPV-and-men-s.htm)

**CDC: HPV Vaccine Questions and Answers Fact Sheet**
Printable version available at: http://www.cdc.gov/std/healthcomm/fact_sheets.htm
(Spanish version: http://www.cdc.gov/STD/Spanish/STDFact-hpv-vaccine-young-women-s.htm)

**American Cancer Society (ACS)**
http://www.cancer.org
1-800-ACS-2345 (1-800-227-2345)

**ACS: What Women Should Know About Cervical Cancer**
Brochure Number: 2004700
To order free versions of brochure: http://www.cancer.org/asp/freebrochures/fb_global.asp?navToScreen=fb_0
ACS: Thinking About Testing for HPV  
Brochure Number: 204740  
To order free versions of brochure: http://www.cancer.org/asp/freebrochures/fb_global.asp?navToScreen=fb_0

National Cancer Institute (NCI)  
http://www.cancer.gov  
1-800-4-CANCER (1-800-422-6237)

NCI: Understanding Cervical Cancer Changes  
Brochure Number: 02-5199  
To order free versions of booklet:  
(Spanish version: http://www.cancer.gov/espanol/tipos/cuello-uterino)

Merck & Co.  
http://www.merck.com

Merck: Gardasil ® (the HPV Vaccine)  
(Spanish version: http://www.gardasil.com/espanol/index.html)

For additional information on cervical cancer and HPV educational resources for the general public, please refer to the following articles:


Resources for the Health Care Providers:

Centers for Disease Control and Prevention (CDC)  
Division of STD Prevention  
http://www.cdc.gov/std  
1-800-CDC-INFO (1-800-232-4636)

CDC: HPV Information for Clinicians  

CDC: HPV Vaccine Information for Clinicians  

American Society for Colposcopy and Cervical Pathology (ASCCP)  
1-800-787-7227 | http://www.asccp.org

ASCCP: Educate the Educator (For Clinicians)  
Accessible online at: http://www.asccp.org/hpv.shtml

Resources compiled by Sharon Bond, PhD, CNM (bondsm@musc.edu), Medical University of South Carolina and Heather M. Brandt, PhD (hbrandt@sc.edu), University of South Carolina. All links provided were active as of September 30, 2009.
With the impending changes that health reform may bring, the family of medicine has more reason than ever to remain connected, unified, and informed. Membership in the SCMA Alliance provides opportunity to become involved in the health care dialog on behalf of our spouses, to make a difference in our communities through volunteer efforts, and to experience personal growth and enrichment through leadership and networking.

The South Carolina Medical Association Alliance is an organization of physicians’ spouses whose mission is to educate, advocate and provide charitable support for the family of medicine, while partnering with the SCMA to improve the health and quality of life for all who live in South Carolina. The Alliance encourages its members to participate in health-related projects and charitable endeavors, and provides support and resources to county alliances throughout the state.

In recent years the AMA and the AMA Alliance have honored the SCMA Alliance with two of their most prestigious awards: the Belle-Chenault Award for Political Participation and the Legislative Education and Awareness Promotion (LEAP) Award for passage of the Shaken Baby Syndrome Education Law. With over 1000 members, the Alliance is an advocate with a strong voice for the physicians of South Carolina.

Is your spouse a member? If not, we ask you to encourage him/her to join. Even if they cannot actively participate, dues help to support many Alliance programs. If you are a current member, we thank you for your support.

Regular membership in the SCMA Alliance is open to the spouse, widow, or widower (provided that person has not remarried outside the profession) of a member of the SCMA. Resident Physician/Medical Student Spouse is a separate category for the spouse of a medical school student or the spouse of an intern, resident or fellow in a training program approved by the SCMA.

If your spouse is interested in joining the SCMA Alliance, please complete the following information and send it to:
SCMA Alliance, P.O. Box 11188, Columbia, SC 29211.

Name____________________________________________________________________________________________
Street Address_____________________________________________________________________________________
City__________________________________ County_______________________________________ Zip__________
Phone ( )_____________________________ E mail______________________________________________________
SCMA Updates

Medicaid

Bulletins

The South Carolina Department of Health and Human Services has issued the following Medicaid Bulletins that impact coverage and/or reimbursement policies for physicians.

• Coverage and rate updates for Synagis® on October 8, 2009. Effective for dates of service on or after October 15, 2009, and no later than March 31, 2010, up to five doses of Synagis® will be covered for infants born between 32 and 35 weeks gestation that meet established risk factors.

• A Pharmaceutical Care Coordination program for children six years of age and younger who are taking antipsychotic or sedative medications to treat mental and behavioral health disorders was implemented effective November 1, 2009. First Health Services Corporation, Medicaid’s Point of Sale contractor, will manage this program. Prescribers will be contacted to ensure appropriate monitoring of patients receiving these medications and to communicate any concerns identified during interaction with the beneficiaries.

• Several revisions to the Managed Care Organizations contract were implemented effective October 1, 2009. Private rehabilitative and chiropractic services will now be included in the core benefit package of Managed Care Organizations. Providers must now contact the Managed Care Organization for contractual arrangements and/or billing requirement before rendering these services to members enrolled in a managed care program. Additionally, Managed Care Organizations are responsible for all hospital claims associated with newborns delivered by mothers enrolled in Managed Care plans on dates of delivery, regardless of hospital length of stay. Previously, the Department was responsible for newborn stays greater than 15 days.

• Reimbursement to Physician Assistants was revised effective November 1, 2009. Previously, Physician Assistants were reimbursed directly for patients receiving both Medicare and Medicaid benefits. Now, Physician Assistants will only be reimbursed directly for dually eligible beneficiaries who are also considered Qualified Medicare Beneficiaries. All other services rendered by the Physician Assistant must be performed under the direct supervision of a physician and billed under the supervising physician’s National Provider Identifier number.

• A revised Preferred Drug List became effective on October 28, 2009. Revisions were made to the following therapeutic classes: Short Acting Beta Adrenergics, Beta – Adrenergic Agents: NEBS, Beta Blockers – Glaucoma, Electrolyte Depleters, Endothelin Receptor Antagonists (ETRA), Beta Adrenergic/Corticosteroid, Herpes Antivirals, and Ophthalmic Antihistamines.

• Copies of the bulletins are available on the DHHS website at the following link:
  • http://www.scdhhs.gov/whatsnew.asp

Medicare

Coverage Decision

The Centers for Medicare and Medicaid Services (CMS) was asked to reconsider the National Coverage Determinations Manual to end the prospective data collection requirements for FDG PET for initial staging of cervical cancer. CMS concluded that results of FDG PET imaging for cervical cancer staging of beneficiaries diagnosed with cervical cancer are used by the treating physician to make meaningful changes in therapeutic management and improve health outcomes, and thus are reasonable and necessary. Therefore, CMS will cover only one FDG PET for staging for beneficiaries who have biopsy proven cervical cancer when the beneficiary’s treating physician determines that the FDG PET study is needed to determine the location and/or extent of the tumor for the following therapeutic purposes related to the initial treatment strategy:

• To determine whether or not the beneficiary is an appropriate candidate for an invasive diagnostic or therapeutic procedure; or
• To determine the optimal anatomic location for an invasive procedure; or
• To determine the anatomic extent of tumor when the recommended anti-tumor treatment reasonably depends on the extent of the tumor.

Additionally, the Centers for Medicare and Medicaid Services found no credible evidence that the results of FDG PET imaging
are useful to make the initial diagnosis of cervical cancer. Therefore, FDG PET for this indication is noncovered.

Medicare Remit EasyPrint (MREP) Software
Free Medicare Remit EasyPrint software is now available to view and print the ANSI 835. You may download the 2.7 version at the following link:
http://www.palmettogba.com/palmetto/Providers.nsf/vMasterDID/7GLUQP0052?opendocument

Inpatient Only Procedures
The Centers for Medicare and Medicaid Services has designated certain procedures as “inpatient only,” which means that these procedures are only covered when performed in inpatient settings. These codes are updated on an annual basis and posted in the Federal Register.

Extavia Billing and Coding Guidelines
The Food and Drug Administration granted approval for Extavia, an interferon beta indicated for the treatment of relapsing forms of multiple sclerosis. Generally, this drug is self-administered by subcutaneous injection. If Extavia administration requires direct supervision of a physician, providers should use HCPCS code J1830 and submit the reason physician supervision was required with the redetermination.

Humana

Preauthorization and Notification Lists
Humana has published its Medicare and Commercial Preauthorization and Notification Lists that will become effective on January 24, 2010. These lists can be accessed at the following link: http://www.humana.com/providers/tools/claims/pre_authorization.asp

Tricare

Pharmacy Program Update
A new Pharmacy Program contract became effective on November 4, 2009. Express Scripts will continue as the program administrator. Tricare anticipates that the transition to the new contract will be transparent to your patients. A new Specialty Mediation Care Management program will provide beneficiaries with enhanced education about specialty medications to promote safe use.
January 2010

Friday - Saturday                      January 8-9, 2010
Charleston Marriott – Charleston, SC
Epilepsy Boot Camp
SPONSOR: Medical University of South Carolina
DESCRIPTION: The purpose of this conference is to increase the understanding of seizure disorders, including terminology, diagnosis, and the impact of epilepsy; increase dialog among various disciplines that care for epilepsy patients; and increase attendees’ awareness of the latest advances in epilepsy pathophysiology, diagnosis and treatment.
TARGET AUDIENCE: Nurses (Neuro); Physicians (Neurology, Neurosurgery, Family Medicine, Pediatrics, ED, Internal Medicine); Neurphysiology technologists; Other staff and administrators
FACULTY: MUSC faculty
TUITION: TBA
CONTACT: Elizabeth Gossen (843) 876-1925
CREDITS: Approx 9.0 AMA PRA Category 1 Credits™

Friday - Sunday                     January 29-31, 2010
Charleston, SC
South Carolina Psychiatric Association (SCPA)
2010 Annual Meeting
SPONSOR: SCPA and SCMA
DESCRIPTION: Speaking topics will enable psychiatrists to be more informed about new psychiatric breakthroughs.
TARGET AUDIENCE: SC Psychiatrists and national Psychiatrists
FACULTY: multiple
TUITION: $160 members, $200 non-members, $25 Residents
CONTACT: Pamela Trapp (803)798-6207 x242
CREDITS: Approx 28 AMA PRA Category 1 Credits™

February 2010

Tuesday - Wednesday         February 16-17, 2010
Charlotte Area Health Education Center (AHEC)
QI 101: A Toolbox for Improvement
SPONSOR: Charlotte AHEC and The NC AHEC Program
DESCRIPTION: QI 101 is a professional development program that builds skills and knowledge among participating hospitals, health departments and clinical practices to accelerate the application of quality improvement methods.
TARGET AUDIENCE: Physicians, RNs, Office Managers, Patient Safety Coord., Case Managers, Quality Improvement Fellows
FACULTY: Multiple, see brochure
TUITION: $750 NC Residents; $1000 SC Residents (tuition partly underwritten by NC AHEC for NC Residents)
CONTACT: Mary Webster, MSN, RN (704) 512-6545
CREDITS: Approx 28 AMA PRA Category 1 Credits™

Thursday                          February 18, 2010
Summit Club, Columbia, SC
South Carolina Urological Association (SCUA)
2010 Annual Meeting
SPONSOR: SCUA and SCMA
DESCRIPTION: Speaking topics will enable urologists to be more informed about breakthroughs in urology.
TARGET AUDIENCE: Urologists and Urology practice administrators
FACULTY: Multiple
TUITION: $35 members, $45 non-members, $35 administrators
CONTACT: Pamela Trapp (803)798-6207 x242
CREDITS: Approx 2.5 AMA PRA Category 1 Credits™

Thursday-Sunday               February 25-28, 2010
Charleston Place Hotel, Charleston, SC
12th ART of Donor Oocytes and Third Party Reproduction Conference
SPONSOR: Village Fertility Pharmacy and SCMA
DESCRIPTION: The symposium will focus on the technology of oocyte donation and third party reproduction in assisted reproductive technology. TARGET AUDIENCE: Reproductive endocrinologist, fellows, laboratory professionals, nurses, mental health professionals in the rapidly expanding segment of in-vitro fertilization.
FACULTY: Karen Hammond, MSN, CRNP; Grant W Patterson, Jr., MD; John A Schnorr, MD; Nora Bolger, RN; Melissa Brisman, Esq.; Susan Crockin, Esq.; David Hoffmann, MD; Maria Jackson, RN, MA; Hannah Lind, RN; Richard Paulson, MD; Linda Romano, BSN, RN; Michael Slowley, MD; Michael Steinkampf, MD; Michael Tucker, PhD; Greg Zola; and Julianne E Zweifel, PhD
TUITION: $700 Physicians/Laboratory directors, PhDs, Attorneys and all industry
CONTACT: Tammy Faust (843) 856-5150
CREDITS: Approx 13.5 AMA PRA Category 1 Credits™

March 2010

Friday - Sunday               March 12-14, 2010
Wild Dunes Resort □ Charleston, SC
20th Annual Pulmonary and Critical Care Conference
SPONSOR: Medical University of South Carolina
DESCRIPTION: The 20th Charleston Pulmonary and Critical Care symposium is designed to provide a clinical update in pulmonary and critical care medicine. This three half-day course will emphasize a practical approach to patients using a pathophysiologic basis for a rational approach to therapy. All sessions will employ an interactive format that will allow the participant to assess his/her current knowledge base. A q&a panel discussion will follow the didactic presentations that will allow the course participants to elicit expert opinions.
TARGET AUDIENCE: Pulmonologist, critical care physician, internist, and thoracic surgeon
FACULTY: Guest and MUSC faculty
TUITION: Physicians in practice $400; Physicians in training/nurses/paramedics/PAs $300
CONTACT: Elizabeth Gossen (843) 876-1925
CREDITS: Approx TBA AMA PRA Category 1 Credits™

Friday - Sunday               March 19-21, 2010
Frances Marion Hotel □ Charleston, SC
2010 Sports Medicine Spring Symposium
SPONSOR: Medical University of South Carolina
DESCRIPTION: This activity is designed for those who deal with athletes of any age
TARGET AUDIENCE: Pediatricians, family practitioners, internists, emergency physicians, physical therapists, athletic trainers, PAs, NPs, fitness trainers, team physicians and orthopaedic surgeons.
FACULTY: Guest and MUSC faculty
TUITION: Physicians in practice $475; Physicians in training/nurses/paramedics/PAs $355
CONTACT: Elizabeth Gossen (843) 876-1925
CREDITS: Approx TBA AMA PRA Category 1 Credits™

Saturday                                         March 27, 2010
Greenville Memorial Hospital - Greenville, SC
3rd Annual GHS Multidisciplinary Cancer Conference: Changing Paradigms in the Management of Melanoma
SPONSOR: Greenville Hospital System University Medical Center
DESCRIPTION: The goal of this program is to increase awareness of the evolving paradigms in the treatment of melanoma.
TARGET AUDIENCE: Primary care, dermatologists, surgeons, medical oncologists and internists
FACULTY: Brian P McKinley, MD, FACS; John Kane, MD; John Maize Sr., MD
TUITION: $50.00
CONTACT: Amanda Gillespie (864) 455-6478
CREDITS: Approx 5.25 AMA PRA Category 1 Credits™
The SCMA Legal Resource Center Answers Your Questions on Minor Law in South Carolina:

**A minor patient is seeking treatment. Is parental consent necessary?**

South Carolina Code § 63-5-310 et seq. provides guidance concerning minors.

In particular, South Carolina Code Ann. § 63-5-340 provides that a minor “sixteen years old or over may consent to health services other than operations,” and that:

Any minor who has reached the age of sixteen years may consent to any health services from a person authorized by law to render the particular health service for himself and the consent of no other person shall be necessary unless such involves an operation which shall be performed only if such is essential to the health or life of such child in the opinion of the performing physician and a consultant physician if one is available.

Further, South Carolina Code § 63-5-350 provides that certain health services of any kind may be rendered to minor of any age without consent of a parent or guardian “when, in the judgment of a person authorized by law to render a particular health service, such services are deemed necessary unless such involves an operation which shall be performed only if such is essential to the health or life of such child in the opinion of the performing physician and a consultant physician if one is available.”

Finally, regarding consent for treatment of a minor’s child, South Carolina Code § 63-5-360 states: “Any minor who has been married or has borne a child may consent to health services for the child.”

**How long must we retain a minor’s medical records?**

According to South Carolina Code Section 44-115-120, physicians shall retain their records for at least thirteen years for minors. This minimum recordkeeping period begins to run from the last date of treatment. After these minimum recordkeeping periods, the records may be destroyed.
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