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A Hotbed of Cancer
Cancer death rates in Appalachia are among the highest in the nation.

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Cancer in Rural America
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By Sue Rochman

The Culture and Cancer of Rural Poverty

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By Sue Rochman

Photographs by Charles Bertram

When Bruce Behringer gave a presentation on cancer last year, he began by telling a story. It started with the number 44.

"This," the cancer researcher said, "was our state's ranking in cancer incidence from 2000 to 2004." Behringer, who is the executive director of the Office of Rural and Community Health and Community Partnerships at East Tennessee State University in Johnson City, then showed the number 20. "And this," he said, "is where we were in 2005."

But just as Behringer's audience began to consider this dramatic jump in the state's cancer diagnosis ranking, an even more alarming number appeared in his next Powerpoint slide: six. "This," he intoned, "was our state's ranking in cancer mortality from 2000 to 2004."

Finally, Behringer showed the number three. "Folks," he said, "this is not the University of Tennessee's football ranking. And it's not the Lady Vols' rank in basketball. We were No. 3 in the country in cancer mortality in 2005. And that's not where we want to be."

Behringer and other experts on rural cancer disparities can rattle off dispiriting statistics with ease: poverty rates; unemployment rates; the number of hospitals or physicians in a region. But, they are quick to point out, these figures can only partially explain the low cancer-screening rates and late-stage diagnoses—and the correspondingly high cancer death rates—that are emblematic of rural regions. Less quantifiable, but no less significant, they note, is the culture of rural poverty and the inroads it provides to cancer cells.

And in the United States, there are few areas that demonstrate as clearly as the Appalachian region the extent of this problem—and what is required to overcome it.

The Appalachian Region

Appalachia is a 205,000-square-mile area that is home to 24.8 million people, of whom 42 percent are rural residents (compared with 20 percent of the U.S. population). The region begins in southern New York state and ends in northern Mississippi. Spanning 420 counties and crossing 13 states, it incorporates all of West Virginia, and includes parts of Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee and Virginia.

To geographers, Appalachia is distinguished by the mountain range that runs

through the region. To epidemiologists, it is a hotbed of cancer. Six of the seven U.S. states with the highest cancer death rates are part of Appalachia, and most of the other Appalachian states are not far behind. (Since Behringer gave his presentation last year, Tennessee's ranking dropped slightly from 3rd to 5th.)

People in Appalachia aren't unconcerned about cancer. They know the stories of the people behind the statistics, and many are downright scared that they, too, will be given a cancer diagnosis. But for many, the area's pervasive and persistent poverty means concerns about cancer are almost a privilege. This year, the Appalachian Regional Commission, a federally funded economic development agency, categorized 82 of the region's 420 counties as economically "distressed" because they ranked in the worst 10 percent of the nation's counties on three economic indicators: three-year average unemployment rate, per capita market income, and poverty rate. Another 79 counties were labeled "at risk."

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For many people in this region, distressed is a way of life. Some live in homes that lack access to clean drinking water. Many lack health insurance or have health plans with high deductibles. Others must weigh the benefit of a cancer screening test against the cost of gas to drive to an appointment or the loss of a day's wages. For people struggling to pay rent, clothe their children, and put food on the table, not surprisingly, the day-to-day needs often win.

A Community Approach

Probably no one understands this better than the researchers who are the backbone of the Appalachia Community Cancer Network (ACCN), a National Cancer Institute (NCI) program aimed at reducing cancer health disparities in the Appalachian region. Since 1992, NCI-funded efforts have helped Appalachian communities increase cancer awareness, develop outreach tools, and improve their access to clinical trials. The ACCN's current projects focus on developing and implementing programs for the prevention and early detection of cervical, colorectal and lung cancer in seven Appalachian states that have high rates of these diseases: Kentucky, Maryland, New York, Ohio, Pennsylvania, Virginia and West Virginia.

Mark Dignan, a cancer researcher at the University of Kentucky, in Lexington, currently leads the ACCN. Over the network's 18-year history, its research has tackled many different areas of cancer prevention, detection and treatment. But, says Dignan, one thing hasn't changed. "We focus on developing community coalitions and grassroots initiatives," he says, "so that the community can show us how to define the problems and come up with solutions."

This type of collaborative approach is called community-based participatory research, and both patient advocates and cancer researchers are trying to harness its potential to improve cancer care in disadvantaged regions. "People in rural areas are often wary of outsiders," explains Joel Halverson, a cancer researcher at West Virginia University's School of Pharmacy, in Morgantown, who studies the geography of health inequalities. "That's another reason why community-based work is so important. It gets local people involved, and empowers them to help make changes in the community."

Halverson tells a story that illustrates this. "I went to a conference on social marketing," he says, "where we discussed a community in which children were being injured in car accidents because they were not in car seats. The researchers went to the community and spoke with community members about designing an intervention. They learned that people weren't using car seats because they believed in God's will, and that if God wanted to take a baby, he would. So, they developed a brilliant solution: They took all of these car seats and had them blessed in the church, which was sufficient to get people to start using them."

Whether it's car seats or cancer, the same rule holds true: Investigators must

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Community Norms

Cervical, colorectal and lung cancer are, theoretically, three of the easiest cancers to prevent. Both cervical and colorectal cancer have screening tests that enable doctors to find and treat precancerous lesions, thereby preventing these diseases from occurring. And although there is no screening test for lung cancer, it's well-known that one lifestyle factor—smoking—is responsible for the vast majority of these cancers.

This means that when researchers look at Appalachia and see the highest cervical cancer death rate in the U.S., they observe not only a disturbing problem but a real possibility: to work with community members to develop programs that may reduce the incidence and mortality of the disease by at least 80 percent.

This is precisely what Electra D. Paskett, an epidemiologist at the Comprehensive Cancer Center at Ohio State University, in Columbus, and her colleagues did when they started a cervical cancer education program in Ohio's Appalachian mountain region. Before getting started, Paskett's team convened a focus group of community members. One of the first things the researchers learned, she says, was that, in some settings, "it was not acceptable to use the word 'cervical' or even the word 'cancer' "—something many outsiders might never have known.

As a result, Paskett and her colleagues knew that calling their education program something like Cervical Cancer Awareness wouldn't fly. Instead, they named it the CARE Project, for Community Awareness, Resources and Education. "It's not that people don't want to hear about cervical cancer," Paskett explains. "They do—they just don't want it advertised. And there's nothing wrong with that. It's just something we need to understand."

Investigators also have learned that just as some community norms can restrict talk of cancer, other community values could support their educational efforts. This was something Nancy E. Schoenberg, a behavioral scientist at the University of Kentucky, in Lexington, discovered when she and her colleagues began to work with women in Appalachian Kentucky to implement an NCI-funded cervical cancer screening program. As they traveled through the area, Schoenberg recalls, it became clear that the prominent role of the region's churches, as both gathering places and touchstones of community values, could provide a framework for their project.

The end result: Faith Moves Mountains, a faith-based program, targeted at women ages 40 to 64, which uses church networks to teach women how to discuss cervical cancer screening with other women in their communities. To date, more than 400 women at 30 churches in four counties have completed the training program. Schoenberg traces the program's success to the influence that

community members can have on those who know and trust them—and to the fact that local community members themselves helped develop the program. “This was not something that was created by outsiders,” she explains.

Genevieve Combs, 62, is one of the women who has benefited. Combs runs the Beckham Combs Community Center, in Vest, Ky., which is where she first attended a Faith Moves Mountains presentation four years ago, and where she now provides other women with information about cervical cancer screening. Prior to attending the educational program, Combs says, it had been years since she had been screened for the cancer with a Pap test. “I kept putting it off,” she recalls, “because it was one of those things I dreaded doing, and that’s what you do with things you dread.”

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Combs' Pap test came back normal. But two years later, after making an appointment with her family doctor because she had become uncomfortable when lying on her stomach, Combs was diagnosed with a different disease: stage I ovarian cancer. The hospital where she had surgery—the University of Kentucky in Lexington—was a two-hour drive away. Fortunately, she was able to have her chemotherapy treatments at a clinic only 30 minutes from her home. This relative convenience proved to be a blessing when her cancer returned and she required another year's worth of chemotherapy, which she finished last November.

Combs says that because of Faith Moves Mountains, she has seen "more women who are willing to talk about cervical cancer." But her peers have also learned a lot by how open Combs has been about her own cancer diagnosis. "I was working while having chemo, and so many of the people here think I'm a hero," she says. "I don't know about that. But I do hope that what I've gone through helps them in some way in taking care of themselves."

The Best Test?

Between 1999 and 2004, the colorectal cancer death rate was 118 per 100,000 for Americans age 65 and older. But in many parts of Appalachia the rate was significantly higher. In the counties considered distressed, the rate was 126 per 100,000 residents, and in other areas it was even worse—137 in Appalachian Ohio and 132 in West Virginia. As with cervical cancer, these numbers reflect not just a problem but also an opportunity: The death rate could easily be reduced if more people get screened for colorectal cancer.

Currently there are seven different tests that can be used to screen for colorectal cancer. Of these, colonoscopy, which screens the lower and upper parts of the colon, is often referred to as the gold standard. It can both detect the disease and prevent it (by enabling doctors to remove precancerous polyps) and it reduces mortality by 60 to 70 percent. Yet a survey, reported by the Kentucky Department for Public Health and the U.S. Centers for Disease Control and Prevention in 2002, showed that only 38 percent of residents in Appalachian Kentucky had ever had a colonoscopy or a sigmoidoscopy, a similar test that screens only the lower part of the colon. In comparison, 46 percent of non-Appalachian Kentuckians and 48 percent of people in the U.S. as a whole had one of these tests.

The problem is access: It's not uncommon for someone in Appalachia to have to travel 100 miles or more to see a specialist who can perform a colonoscopy. And that requires not only a car, but the gas money to get there and back and

someone who can accompany the patient to the appointment—a necessity because the test requires sedation. What happens, says Dignan, is that patients "start thinking things like, 'Am I really susceptible to this disease? How likely am I to really have it?' And as you think about it, it's easy to talk yourself out of doing it."

This, in turn, can lead to a communication gap of sorts, between a doctor who believes he is acting in a patient's best interest by recommending a colonoscopy, and a patient who is thinking about all of the test's requirements and costs and never goes. But, Dignan notes, if a doctor shifts gears, and tells a patient about the fecal occult blood test (FOBT), a screening test that can't prevent colorectal cancer but can detect it early—and that can be done at home—the chances are greater that the person will actually be screened. And although the FOBT may not be the "gold standard," having the test done annually can reduce the risk of dying of colorectal cancer by 15 to 33 percent.

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The benefit of the FOBT approach was illustrated in a study conducted by Samuel Lesko, a family practitioner who directs the Northeast Regional Cancer Institute in Scranton, Pa. Lesko surveyed nearly 300 doctors in northeastern Pennsylvania, where the incidence of colorectal cancer is 30 percent higher than the national average. He found that doctors who thought the FOBT was valuable were about half as likely to have patients diagnosed with advanced-stage disease as doctors who thought the FOBT was not worth using.

"I think this tells us," Lesko says, "that the doctors who recommend the FOBT are probably the doctors who do a good job of making sure their patients are being screened for colorectal cancer." These also are the doctors who can differentiate between what is "best" on paper and what is "best" for a specific community.

The Christmas Crop

In general, lung cancer incidence and death rates are higher in Appalachia than they are in other areas of the country—and there is little doubt that smoking is a contributing factor. Studies have found that about 30 percent of people in rural areas use tobacco, and in some parts of Appalachia the rates are even higher.

In Kentucky, for example, one survey found that nearly 35 percent of women of childbearing age are smokers, compared with a national average of about 22 percent. Likewise, about 26 percent of pregnant women smoke, compared with just under 11 percent of pregnant women nationwide. Studies also have found that children in rural areas tend to begin smoking at a younger age than do children who grow up in urban areas. In addition, rural teens are two to three times as likely as urban teens to regularly use chewing tobacco.

These statistics reflect the fact that for many people in Appalachia smoking is a deeply rooted norm. "Tobacco used to be called the Christmas crop," explains Behringer, "because you'd harvest it in November and the money you got from selling it was what you had for Christmas presents." For many, it was the family's economic backbone. "People who grew up here will tell you that the only reason they got to go to college or could buy a home was because they grew tobacco," he says. "It was the only way to make money. So, when people come in and attack tobacco growers, they are not only attacking the regional culture and a whole way of life, but telling people that what their father and grandfather did was wrong."

This means that, to be successful, smoking-cessation programs must acknowledge, and not condemn, the central role tobacco has played in the region. And the programs that appear to work best, says Behringer, are the ones that not only are run by locals but that also address the habit of smoking rather than tobacco itself. For example, one study conducted in the Appalachian parts of Ohio found that about 18 percent of women smokers who were counseled by

lay health educators from their area stopped smoking after three months. That's compared with just under 2 percent of women smokers who received letters from their physicians suggesting they make an appointment to learn how to quit.

Yet as hard as it might be to persuade smokers to consider quitting, it is more difficult to help them give up the habit for good. "Everyone would start out excited about having decided to quit," says Johnna Miller, 48, a former smoker who worked as a lay health educator for eight years in these studies. "But by my third visit I could tell who would be successful. That's when they'd tell me they'd gone out with a friend who smoked, and lost their resolve. … Or they'd be living with a household of smokers and be the one person trying to quit."

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"It's a heartbreaking habit," says Miller. "And there is a lot of denial in Appalachia that smoking is bad for you. If I had a dime for every time someone told me that their grandmother smoked and that she lived to be 95, I'd be a wealthy woman."

Telling the Tale

The poverty and lack of education that are endemic to Appalachia contribute to the region's low cancer-screening rates and high smoking rates. They also put patients at a disadvantage when confronted with a disease as complex as cancer. "One of the largest issues we found when we spent time with people in eastern Tennessee," says Behringer, "was that people said they often didn't understand what their doctor had told them."

Part of the problem, Behringer explains, is the education gap between the physicians and the people to whom they provide services. Nearly a quarter of adults living in Appalachia do not have a high school diploma. As a result, some patients do not understand what a doctor is telling them to do, while others don't fully grasp their health situation. "People would tell us how hard it was to talk to their doctor," says Behringer. "They'd tell us how they had tried to tell their doctor about their grandmother who had a similar problem, and how their doctor didn't seem to want to hear it."

As Behringer and his colleagues listened to community members tell these stories, they not only realized the extent to which "storytelling is second nature to the people here," he says, but that this mode of communication had the potential to be used in clinical care. That's why, with a new NCI grant in hand, Behringer and his colleagues are currently developing a program designed to integrate the art of storytelling into the curriculum at the East Tennessee State University College of Medicine.

"We're going to teach the doctors how to listen to their patients," he says. "We're also going to teach them how to break bad news or help patients make sense of what is going on by framing it as a story, so that the patients can then tell their kids or neighbors what is going on and how they can help."

What Behringer and his team hope to teach these young doctors is, in essence, what they have already taught themselves to do: listen to the people they are trying to help. Of course, not every program developed through a community-based participatory approach will be successful. But because the incidence and death rates for cervical, colorectal and lung cancer in this region are so high, the programs that work will have the potential to make a significant and lasting impact. This, in turn, could mean that one day, the children of present-day Appalachia will be hearing stories and telling their own tales about why cancer screening and awareness are so important. CR