

## Understanding the Challenges of Reducing Cancer in Appalachia: Addressing a Place-Based Health Disparity Population

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### Abstract

The Appalachian region of the United States has long been recognized for its poor economic and social indicators. Only during the past decade have multi-state data become more accessible to describe the regions' poor health status and resulting outcomes. A recent community-based participatory study engaged rural Appalachians to describe "what makes Appalachia different?" from other geographic areas and cultural groups in the United States and identify those characteristics that influence the region's health. This article summarizes the community interpretation of these findings.

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### Background

The historic Appalachian region spreads along the mountain spines from the southern tier of New York counties down to the hills of northern Alabama and Mississippi. In 1966 the region was geographically defined in legislation that formed the Appalachian Regional Commission,

a federal-state partnership designed to address Appalachia as a place characterized by poor health, low income, and low educational achievement levels. The region consists of 410 counties in parts of thirteen states (including all of West Virginia) (see Figure 1).

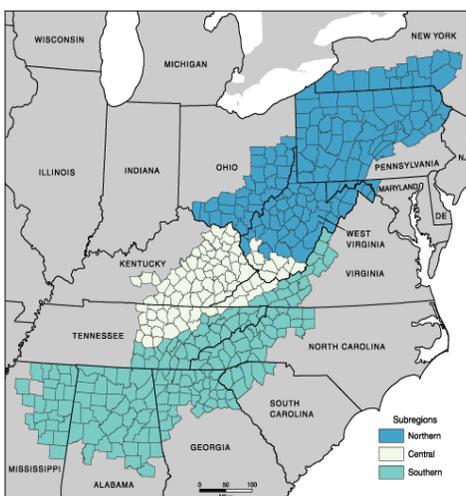


Figure 1  
Appalachia subregions (Northern, Central, and Southern ([ARC](#), 2002)).

Recent advances in the use of geographic information systems (GIS) to report mortality, morbidity and risk data have resulted in preparation of maps that spatially display high mortality clusters in the central Appalachian region (Pickle, Mungiole, Jones & White, 1996). Recognition of place-based disparities is relatively new (Behringer & Friedell, 2006). Studies supported by the Appalachian Regional Commission and Centers for Disease Control and Prevention (CDC) defined the gender, race

and age sub-populations and types of diseases for which apparent disparities in risk and mortality exist. These findings are summarized in Table 1. Appalachian communities' perceptions, interpretations and response to these new disparity findings has not been documented; therefore, his study involved rural Appalachian communities in the review of secondary data analysis and exploration of their interpretation of underlying regional factors for the disparities.

Table 1  
Recent Findings about Health Disparities in Appalachia

Citation	Finding
Huang (2002)	<ul style="list-style-type: none"> <li>• All Cancers and Lung Cancer death rates higher in Appalachia and rural Appalachia than US.</li> <li>• Cervical Cancer death rate higher for Rural Appalachia.</li> <li>• Colorectal cancer death rates are higher for Appalachia.</li> </ul>
Halverson, Ma, Harner, Hanham & Braham (2004)	<ul style="list-style-type: none"> <li>• Geographic areas among Appalachian states have notably high prevalence of overweight and obesity</li> </ul>
Halverson, Ma & Harner (2004)	<ul style="list-style-type: none"> <li>• For most causes of death Appalachian White rates higher than US White rates.</li> <li>• For many causes of death Appalachian African. American rates higher than US African American rates.</li> <li>• Premature mortality rates higher in Appalachia region higher than US rates.</li> </ul>
Lengerich, Tucker, Powell, Colsher, Lehman, Ward (2005)	<ul style="list-style-type: none"> <li>• Incidence of cancer of the lung, colon, rectum and cervix in Appalachia is significantly elevated.</li> <li>• Cancer of lung and cervix in rural Appalachia even more elevated.</li> </ul>
Murray, Kulkarni, & Ezzat (2005)	<ul style="list-style-type: none"> <li>• Poor whites in Appalachia have life expectancy equal to Panama and Mexico.</li> </ul>
Yabroff, Lawrence, King, Mangan, Washington & Yi (2005)	<ul style="list-style-type: none"> <li>• Appalachia identified as one of three national place-based cervical cancer disparity populations.</li> </ul>

Regional analysts have used geographically mapped data that cross state boundaries to uncover new findings about cancer patterns and their outcomes in Appalachian sub-populations (age, gender and race). These maps show regional disparities and facilitate community discussion. For example, a preponderance of the Appalachian population is rural and white. There

are few large cities within the region (e.g., Pittsburgh, PA; Winston Salem, NC; and Birmingham, AL). Given the focus of health disparities research on conditions and outcomes among racial and ethnic populations, attention to the largely white rural Appalachian region is fairly recent. Comparison of white Appalachian mortality to white national mortality rates

indicates higher mortality for all causes of death and for many specific causes of death. Analysis conducted by gender, race and age yielded findings of excess premature white mortality (Halverson, Ma & Harner, 2004). Another researcher described the scope of this issue by equating life expectancy of poor Appalachian whites with life expectancy of the people of Mexico and Panama (Murray, Kulkarni & Ezzat, 2005). Given this scope and severity, drawing new national recognition and attention to Appalachian white disparities is a necessary social justice issue.

A second major and previously undocumented issue emerged from Halverson's 2004 statistical analysis. Mortality rates from all causes combined and many specific causes of death for Appalachian blacks were found to exceed national black mortality rates. This unexpected finding is hidden in customary individual state analyses. High mortality rates among African Americans residing in Appalachian regions of states is usually viewed as an artifact of small population numbers and greater attention is paid to larger numbers of African Americans in non-Appalachian regions (e.g., West Tennessee vs. East Tennessee, Eastern and Southside Virginia vs. Southwest Virginia). However, new multi-state regional analysis of Appalachian populations demonstrates that blacks in Appalachia may be viewed as suffering from a "double disparity." They are part of both the place-based, geographic Appalachian disparities, as well as nationally acknowledged racial disparities. The lack of attention to statistical interpretation of small numbers for Appalachian African Americans is a second important social justice issue.

### **Methods**

The Rural Appalachian Cancer Demonstration Program (RACDP) was a five-year grant funded effort supported through the Centers for Disease Control and Prevention (CDC) designed to study regional cancer disparities in the Appalachian regions of East Tennessee, Southwest Virginia and Eastern Kentucky. Program investigators from East Tennessee State University, the Virginia Department of Health, and the Markey Cancer Center of the University of Kentucky

collaborated in multiple studies. The Program's purpose was to explore, identify, describe and document cancer disparities in the Appalachian regions of the three states. Multiple studies were conducted through this Program, using a mix of quantitative and qualitative methodologies (Rural Appalachian Cancer Demonstration Program, 2006). Investigators determined that community review of findings of Appalachian disparities might lead to new interpretations and additional insights. This approach followed the principles of community-based participatory research (Wallerstein & Duran, 2003) that were used throughout the Program.

Two community Cancer Research Review Work Groups were formed; one in Northeast Tennessee and one in Southwest Virginia. Members were selected because of their reputation as informal community leaders with rich social networks. Membership was mixed by race, age, gender and other social-economic characteristics. The Workgroups consisted of eight and twelve lay community members, all of whom had a personal and community interest in cancer. No practicing clinical health professionals were included in order to assure lay interpretation of results.

Members committed to participate in four two-hour presentation and discussion meetings. Each meeting included a presentation of data reported in a RACDP study. Topics included: a comparison of national and regional cancer mortality patterns; patient-provider health communication issues; cultural factors that influence patient and community beliefs and actions about cancer and cancer care; research design and study issues encountered in rural communities; and an explanation of state cancer control coalition plans. Each topic and discussion was represented in both Workgroups. Discussions were audio-recorded and transcribed verbatim; researchers are currently completing qualitative analysis to identify key community perceptions about Program findings.

One final session combined both Workgroups in a brainstorming exercise to identify specific regional characteristics that might contribute to mortality disparities from cancer and other

causes of death. A two-hour format was used during which members from the combined Workgroups participated in a discussion of general reactions to the Program's disparities research reports. The participants were then challenged to identify "what makes Appalachia different?" from other geographic areas or distinct cultural populations. The question was purposefully left vague in order to elicit multiple types of comments. This approach was successful in that investigators were able to summarize Workgroup participants' responses into three broad themes: geographic characteristics; healthcare system characteristics; and cultural characteristics.

### **Results: What Makes Appalachia Unique?**

Participants stated that they viewed the Appalachian region as having different characteristics from other areas of the country and other defined populations. Participants described their region ("the mountains") as a distinctive "place" that poses several important challenges concerning cancer.

#### **Geographic Characteristics**

- Much of the regional population is rural and lives in small communities.
- Geography isolates many communities from cities and healthcare resources. Mountain chains, valleys and rivers often separate small communities from each other in the same counties and amplify problems such as transportation to healthcare facilities.
- Appalachian residents feel that the mountains shape family lives and create and reinforce a strong personal and culture identity with "place."
- Life and work in the mountains exposes residents to many causes of cancer. These exposures include occupational (work in coal mines, with chemicals in factories, and pesticides in agriculture) and natural environmental (radon) exposures.
- Geographic isolation minimizes exposure to outside healthcare. This includes limited exposure to healthy lifestyle and prevention messages that may be more prevalent in urbanized areas.

- Because of rurality and isolation, community members, regardless of socio-economics and race, share many common exposures and experiences with healthcare.

#### **Healthcare System Characteristics**

- Availability of healthcare services has been historically limited in the mountains. Almost half of all Appalachian rural counties remain federally designated as health professions shortage areas.
- Distance to care remains a common problem for those residing in rural counties.
- Access to care for some residents is limited by economic factors such as lower pre-capita income, higher unemployment and health insurance issues (non-acceptance of public insurance plans, high deductible policies, etc.).
- There is a general level of mistrust among Appalachians, described as the fear of "being taken advantage of" by health care system. This belief seems to result in an under-use of care.
- Too few health providers demonstrate cross-cultural communication competence in their practice, failing to recognize or value beliefs and communication issues prevalent in the region.
- There is a sense of fatalism about using the health care system. Participants stated poor expectations of outcomes of care, particularly relevant to cancer. This sense is based on collective community experiences, for example, in trying to navigate the cancer care system and high community visibility of cases of cancer incidence and mortality.

#### **Cultural Characteristics**

- Personal confidence and trust may be challenging to build with rural Appalachians. Trust is earned over time through multiple positive encounters with health professionals and the health system. Once gained, it is rarely severed.
- There is a general lack of assertiveness among Appalachians that influences their health care. This results in uncertainties in patient-provider communication, issues of compliance with therapeutic regimes, and

difficulties in patient goal setting and decision-making.

- Low health care utilization and a lack of follow-up with referrals are influenced by a regional sense of personal privacy and pride and low expectations among Appalachian residents regarding good health.
- Programs and services that are seen as charity are often rejected.
- There is a strong regional faith in God. Health professionals who acknowledge this faith as part of a rural Appalachian's life and philosophy may be better received by the larger community and the patient-base.
- Minority community members recognize that their small numbers may result in the presence of too few minority health professionals with whom to create trust and long-term relationships.

The results of community comments indicate the depth of concern among members about their region. They provided a rich interpretation of the interplay of the health of the Appalachian region as it is influenced by cultural factors. The results mirror an understanding of the duality of factors that affect population health described by Anderson and Aday (1978): the health services sector and of individuals' knowledge, attitudes, beliefs and behaviors.

### **Discussion: Geographic, Healthcare and Cultural Characteristics: Getting the Health Promotion Implications Right to Address Regional Social Justice Issues**

Discovery of documentable health disparities in the Appalachian region provides a challenge for reconsidering regional responses. The findings from the RACDP Cancer Research Review Work Groups provide rich evidence that could be used to reflect upon how to improve health services to address disparate outcomes. One important component of health care and its related services that could benefit from the findings is health promotion.

Appalachia has been popularly characterized for many years by cultural stereotypes and statistical comparisons. (Coyne, Demian-Popescu & Friend, 2006). Stereotypes of Appalachia took

hold by the late 1800s when journalists, missionaries and travel writers promoted the image of the uneducated, impoverished "hillbilly" (Williams, 2002). Today, economic gains in Appalachia have created a diverse region that is still largely overshadowed by entrenched stereotypes. Even with dramatic changes that have transformed the region (Appalachian Regional Commission, 2005) residents still describe the region using characteristics that can be simultaneously viewed as protective and negative health factors.

The characteristics discussed in this paper reveal implications for health promotion efforts. First, historic isolation appears to be one factor that promotes the centrality of family and community in Appalachia. Suspicion of "outsiders" (e.g., "invasion" of missionaries from the North; stealing of mineral rights; for review see Olson, 1998; Williams, 2002) may have been passed down through the generations, possibly resulting in families and communities tightening their loyalties to ingroup members (and becoming more suspicious of outgroup members (Gudykunst, 2003)). In cultures that emphasize the importance of ingroups, or "we-groups," these groups tend to become the major source of a member's identity and protection; therefore, loyalty to one's ingroups outweighs one's interests and needs (Hofstede, 2001). Understanding this loyalty to "ingroup" is central to the design of successful health promotion efforts to help people change lifestyles and achieve a state of optimal health. The purpose of health promotion programs is to improve awareness, change behavior and create environments that support good health practice (O'Donnell, 1989). The development of regional health promotion programs can use hints identified by RACDP Workgroups to redefine multiple units of program practice that include individuals, health providing organizations, communities and public policy (Green & Kreuter, 1991).

Rather than focusing on bringing singular, independent patients into the healthcare system, Workgroup members suggested that strong family and community social networks should be tapped to deliver health promotion services

and messages. Programs should tap existing networks that include community cancer survivors to partner with patients, serving as informal patient navigators by linking the healthcare system, community, and patient. This recognition of families and support groups as units of solution (Steuart, 1978) can strengthen individual patient interventions.

Second, Workgroup participants wanted to see more local credible sources (e.g., their personal doctors' offices, community libraries, etc.) become proactive in disseminating health information. There are real access barriers faced by rural residents that should be acknowledged and addressed in regional health promotion programs and interventions. One such access barrier was revealed when participants repeatedly expressed frustration with healthcare providers' inability to "translate" medical messages into a simpler and more understandable format. There was ample suggestion that by involving credible ingroup members (e.g., "parish nurses"), the distrust of more traditional sources of health information (e.g., health care providers and government) may be overcome. Programs for rural Appalachians should not simply transfer urban models. Programs should address cultural sensitivity defined by the Workgroups' sense of unique cultural, environmental and economic characteristics.

Third, the issue of patient-provider communication was frequently cited. Rural Appalachians fear being stereotyped (e.g., as the "uneducated hillbilly"), and this acts as a barrier to patients who want to ask questions but are worried about being perceived as unintelligent by health professionals who are "outsiders." Understanding and appreciating the frame of reference of rural Appalachians regarding use of the elements of the continuum of cancer care is an important first step in designing effective health promotion programs. One important clue provided by the Workgroups is to build on the trust engendered by positive encounters and effective communication between patients and their primary care providers. There is apparent contradiction in the findings of distrust of the health system and reliance on primary care

providers. However Workgroup participants urged additional attention and training for providers in Appalachia to improve their effectiveness by recognizing their position of importance and influence in patient, family and community beliefs and behaviors. Patient desire to change is reciprocated by primary care providers who actively encourage screening and play visible roles in community cancer control activities. The absence of encouragement is seen as tacit approval of unproductive beliefs and behaviors. Social-behavioral diagnostic skills are thus important in creating health promotion efforts to build reciprocity into trusting relationships once established.

Fourth, Workgroup participants stated that "good health" is not something that Appalachian communities demand, or to some degree, expect. This finding underscores the notion that the value of health and healthcare must be viewed as multi-factorial in nature as the interaction of personal factors, behavior and environment. Several examples were given. Rural Appalachians may not perceive that the benefits to cancer screening and other preventative health care activities outweigh the costs. This belief and lack of action is borne from the many competing life demands and economic priorities prevalent among rural Appalachian families. Members cited many cases of individuals who felt they had to choose between seeking health care, work and providing for children. Asymptomatic screening was one case in point. Participants saw this as understandably low on a priority list, especially when an individual is coping with the challenges of extended family and other acute health problems. Other life priorities serve as barriers to behavior change (e.g., diet changes, exercise, use of tobacco), cancer screening, diagnosis, and sometimes treatment. They did recognize these barriers also help people avoid the topic of cancer, and result in an overwhelming sense of inability to move "from knowledge to action." This set of findings invites health promotion programs to use the multiple theoretical constructs found the Health Belief Model to plan future program planning.

Finally, members reported that communities learn about cancer care is through observation of

neighbors' care and outcomes. Although participants were generally unaware of health statistics that describe the region's poor health outcomes and the severity of regional cancer disparities, they were not surprised by findings. They know that life in the mountains is hard and expect higher mortality rates. Rural residents seem intimately aware of cancer deaths throughout their social networks of family, social groups (churches and workplace) and communities. Many community misperceptions stem from these observations. For example, they reported that one rural community's impression of cancer screening was that it is associated with a "death sentence." Members acknowledged that the impression is based upon screenings of the neighbors and acquaintances found to have a late-stage cancer diagnosis. However, community impressions once formed are expectations difficult to change. This is the negative side of rural intimacy. Members urged health promotion practitioners to tailor their messages, both written and spoken, to allow Appalachians to become better recipients of accurate information about cancer and cancer care. Such tailoring must include efforts to understand and address the unique geographical, cultural and historical characteristics underlying the regional cancer experience and cancer communication in Appalachia. This work could be informed by health promotion practitioners' use of concepts such as self efficacy, observational learning, and reciprocal determinism included in the Social Cognitive Model (Baranowski, Perry, and Parcel, 1997; Breinbauer & Maddeleno, 2005).

### **Conclusions**

It is clear that data describes Appalachia as a place with cancer and other health disparities. Through participation in Community Cancer Research Review Work Groups, rural residents have identified their beliefs that these disparities are related to multiple geographic, health systems and cultural characteristics. Addressing regional disparities in Appalachia calls for a new view of social justice, one that introduces attention to place-based white and black mortality and premature cancer mortality. The geography of the region has played a major role in determining healthcare expectations. The size

and distribution of rural communities affects distribution of and access to health care resources. Life in Appalachia has also formed distinct cultural influences that influence the self efficacy on health of its residents. Consequently the aphorism coined by Friedell fifteen years ago is particularly relevant to health promotion: "If the problems are in the community, the solutions are in the community," (Friedell, 1991). While social justice calls for a more equitable distribution of health resources and greater access to cancer services in Appalachia, it also frames the challenge improving health promotion programs for Appalachian residents, be they white or black, with special attention to factors associated with the premature mortality that plague the region. Improvements can be made in programs and outcomes if interpersonal and community health communication better reflects the geographic, health systems and cultural characteristics identified by the RACDP.

The Appalachian region has a cancer problem, but the solution of the problem depends on multiple actions taken at the community level to address characteristics that influence and control individual beliefs behaviors. Concerted action to raise the level of awareness of communities to their cancer control challenges must necessarily focus their attention on the availability, accessibility and utilization of health care services, the means through which these challenges can be addressed. The deficiencies in the rural Appalachian health care system will be evident. Solving them will require not only the coordinated efforts of the community, but also seeking the assistance of state cancer control plans, larger medical centers, and regional cancer centers. Seen as "outsiders", these organizations need to be responsive to requests for help from Appalachian community leaders as "inreach centers" for community providers, instead of "outreach centers" whose primary interest is in establishing service outposts in the region. Health promotion programs then need to acknowledge cultural characteristics of the region and develop new strategies to encourage use of services and overcome the multiple barriers faced by residents. Engaging rural communities and their rich social networks may

suggest the use of lay health workers and others who can improve communication about cancer control issues that lead to improved outcomes

and reduced cancer disparities for a long-suffering hidden region of our country.

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