The Mountains Hold Things In:
The Use of Community Research Review Work Groups to Address Cancer Disparities in Appalachia

Sadie P. Hutson, PhD, RN, WHNP, Kelly A. Dorgan, PhD, Amber N. Phillips, MA, and Bruce Behringer, MPH

Purpose/Objectives: To review regional findings about cancer disparities with grass roots community leaders in Appalachia and to identify perspectives about what makes the cancer experience unique in Appalachia.

Research Approach: A community-based participatory approach that includes focus-group methodology.

Setting: Work groups gathered in well-known community locations in northeastern Tennessee and southwestern Virginia.

Participants: 22 lay adult community members (12 in Tennessee and 10 in Virginia), all of whom had a personal and community interest in cancer and were reputed as informal community leaders.

Methodologic Approach: Work groups engaged in a series of five sequential sessions designed to (a) review regional data about cancer disparities and identify perspectives about what makes the cancer experience unique in Appalachia, (b) promote dialogue between the work group members and healthcare providers to identify methods for improved collaboration, and (c) integrate the work group with regional efforts of the states' comprehensive cancer control plans.

Findings: Four major themes emerged from the focus group sessions with each work group: cancer storytelling, cancer collectivism, healthcare challenges, and cancer expectations. The community research review work groups proved to be a successful method to disseminate information about regional cancer disparities.

Conclusions: Study findings provide a unique foundation so that healthcare providers and researchers can begin to address cancer disparities in the Appalachian region.

Interpretation: Nurses are in key positions to partner with trusted community leaders to address disparities across the cancer continuum in Appalachia.

Key Points . . .

➤ The cancer experience in Appalachia appears to be affected uniquely by cultural, economic, and geographic characteristics.

➤ Healthcare professionals and researchers must respect and partner with existing social and familial community networks to address cancer disparities effectively.

➤ The use of community research review work groups is a viable method to examine cancer disparities among traditionally marginalized communities.

Appalachia arguably became the frontline of President Lyndon Johnson's War on Poverty the day he stood on the porch of a house in Kentucky and declared the beginning of an ambitious social and economic battle (Williams, 2002). However, images and stories of crippling poverty (Orslene, 2006) swept out of Appalachia and into lower-lying lands long before then, in part because of writers, such as Horace Kephart (2000) in the early 1900s and Jack Weller (1993) in the 1960s, who delved into descriptions of unkempt, lean, sullen, and isolated mountaineers.

Today, Appalachia is viewed predominantly as "a region of poverty" (Billings, 2006, p. 236). Emerging reports continue to challenge the hypergeneralization of the vast region that stretches from New York to Mississippi and surprisingly holds diverse communities and populations from urban to rural, mountainous to piedmont, thriving to impoverished. Isserman (1996),

who examined statistics for Appalachia as a whole as well as various regional segments, concluded that Appalachia had made strides in decreasing poverty levels and increasing educational attainment and employment levels. Likewise, the Appalachian Regional Commission (n.d.) noted in a recent report that the region is one of contrasting economies and infrastructures. The portions of Appalachia still economically lagging behind the rest of the nation largely are rural, isolated communities (Isserman). Unfortunately, with economic disparities also come health disparities (Behringer, 1994). Geographic isolation and economic conditions have combined to create unique healthcare challenges in mountainous, rural Appalachia (Mulcahy, 2006).

Economic Challenges and Cancer Disparities in Appalachia

The National Institutes of Health (n.d.) traditionally have defined health disparities as "differences in the incidence,

prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States." The recognition of disparities in cancer outcomes appears to have begun with a 1973 publication documenting a significant increase in cancer-related mortality among African Americans from 1950–1967 (Henschke et al., 1973). Since then, numerous documents have explored prevalent gaps in cancer outcomes among various populations in the United States (Behringer & Friedell, 2006; Cunningham & Butler, 2004; Fouad et al., 2004; Friedell, Linville, Rubio, Wagner, & Tucker, 1997; Friedell, Rubio, & Harris, 1994; Heckler, 1985; Lengerich et al., 2005; Office of Disease Prevention and Health Promotion, n.d.; Polednak, 2004).

Early research on disparities focused on the relationship between race and health; however, additional research has emerged, identifying similar challenges in rural Appalachian populations. For example, many areas of Appalachia have been designated federally as healthcare professional shortage areas with inadequate numbers of healthcare providers and inequitable healthcare services (Couto, Simpson, & Harris, 1994). In addition, economic distress, low educational attainment, and environmental characteristics have been linked to adverse health outcomes, particularly in isolated rural mountain communities (Behringer & Friedell, 2006).

Although the economic state of many Appalachian counties continues to improve, disproportionately high cancer-related mortality rates persist (Appalachian Regional Commission, 2004; Friedell et al., 2001); recent findings demonstrate higher rates for selected types of cancers (i.e., cervical, colorectal, and lung) (Armstrong et al., 2004; Bluegrass Coalition for Cancer Screening & Kentucky Medical Association Cancer Committee, 2005; Huang, 2002; Yabroff et al., 2005). Furthermore, a study supported by the Appalachian Regional Commission documented that premature mortality rates in Appalachia exceed the national average because of a number of causes, including cancer (Halverson, Barnett, & Casper, 2002).

Because of the economic, geographic, and cultural diversity of Appalachia, clearly identifying all contributing factors leading to health disparities across the region is difficult. As such, unique research strategies must be undertaken to effectively address cancer disparities faced by these communities.

Methods

Study Context

The Rural Appalachian Cancer Demonstration Program ([RACDP], n.d.), a grant-funded effort supported by the Centers for Disease Control and Prevention, was designed to identify, describe, and document regional cancer disparities in the Appalachian regions of eastern Tennessee, southwestern 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 partnered to conduct multiple studies through the program, using a mix of quantitative and qualitative approaches. Investigators hypothesized that community review of cancer disparities data might lead to new interpretations about what makes the cancer experience unique in Appalachia as well as new approaches for cancer control efforts.

Design

A community-based participatory research approach theoretically and methodologically guided the study (Wallerstein & Duran, 2006); it has been used widely to help explain complex public health issues and their impact on various populations (Butterfoss, Goodman, & Wandersman, 1993; Green & Mercer, 2001; Israel, Eng, Schultz, & Parker, 2005; Israel, Schulz, Parker, & Becker, 1998). Community-based participatory research is a unique approach to investigating community-based problems by equitably involving academic and community partners in the process and products of research. Recent reports highlight the success of the approach to address health disparities in Appalachia (Coughlin et al., 2006; Denham, Meyer, Toborg, & Mande, 2004; Huttlinger, Schaller-Ayers, & Lawson, 2004); therefore, the approach was undertaken by RACDP investigators. The approach led to the identification of statistical disparities in cancer and then possible strategies to address the disparities, including the formation of work groups for a substudy investigation.

Sample and Setting

Two community research review work groups, one in northeastern Tennessee and the other in southwestern Virginia, were organized. The work groups consisted of 22 lay community members (12 in Tennessee and 10 in Virginia), all of whom had personal and community interests in cancer (e.g., cancer survivor or caregiver, community advocate). Work group members were selected because of their reputations as informal community leaders with rich social networks and professions such as librarian, pastor, educator, attorney, and housekeeper. In Tennessee, community members with experience in health-oriented community councils, committees, or volunteer activities were identified by RACDP staff. In Virginia, work group members were recruited through a nonprofit healthcare professions training program office with strong ties to rural leaders who had demonstrated interest and involvement in health. Professional background, age, gender, race and ethnicity, and socioeconomic background purposefully were mixed for the convenience samples; however, both groups primarily were comprised of white, non-Hispanic, middle-class individuals.

Data Collection

Following informed consent procedures, each work group convened in a well-known community location in their respective states. The work groups engaged in a series of five sequential sessions designed to (a) review regional data about cancer disparities and identify perspectives about what makes the cancer experience unique in Appalachia, (b) promote dialogue between work group members and healthcare professions faculty to identify methods for improved collaboration, and (c) integrate the work group with regional efforts of their respective state comprehensive cancer control plans.

Faculty facilitators engaged work groups in discussions of RACDP research findings using a semistructured moderator guide. Sessions began with a 30-minute topical presentation to stimulate thought and subsequent discussion (see Table 1). Each session lasted approximately two hours. Presentations essentially were equivalent in each state, except for specific details of the state comprehensive cancer control plan. The study concluded with the fifth session, which convened work groups and RACDP investigators for further interpretation of the

Table 1. Focus Group Session Intents and Desired Outcomes

Session	Session Intent	Desired Outcome
1	Cancer disparities findings (RACDP and Appalachian Regional Commission studies)	Interpretation of findings Questions raised by work group members
2	Communication issues in cancer care	Health literacy and communication styles Effect on cancer outcomes
3	Research: methods and human subjects protection	Sociocultural issues Engaging communities in research about cancer
4	State cancer control plan: elements, process, and community involvement	Health information Dissemination in Appalachia
5	Integrated work group review	What makes experiences with cancer in Appalachia unique? Recommendations for practice and research

RACDP—Rural Appalachian Cancer Demonstration Program

inductively derived findings in an exercise to identify specific regional characteristics that might contribute to cancer mortality disparities. During the last session, work group members were challenged to identify what makes Appalachia unique from other geographic areas or distinct cultural populations. The question was intentionally vague to elicit diverse commentary.

Analysis

All focus group sessions were audio recorded and transcribed verbatim; NVivo® 2.0 (QSR International) facilitated qualitative content analysis of the narrative data. The goal of that type of analysis is the formation of themes from the observation of verbal and nonverbal data cues and the coding of those data (Neuendorf, 2002). The work group facilitators independently coded and analyzed all transcript data. Coding and analytic discrepancies were reconciled through discussion and external peer review of findings by RACDP principal investigators.

Results

Four major themes emerged from the focus group sessions with the work groups: cancer storytelling, cancer collectivism, healthcare challenges, and cancer expectations. Given the nature of cancer as a multifaceted health condition, the themes are interrelated rather than mutually exclusive. In the aggregate, the themes depict the unique cancer experiences in the Appalachian region.

Cancer Storytelling

The cancer experience in Appalachia may be unique, in part, because of the region's storytelling tradition. Cancer stories appear to be trapped in rural, mountainous communities, spreading within and between families and influencing perceptions about health, health care, and cancer in Appalachia.

Cancer everywhere: One emergent subtheme surrounding cancer stories involved the ubiquitous nature of cancer in Appalachia. A participant explained that "[community members] expect to get [cancer]. They all do. It's almost like it's inevitable." In addition, evidence that stories were passed to younger generations also emerged. When stories passed from one generation to the next, fear and anxiety appeared to be transferred, thereby passing along cancer screening beliefs and behaviors. People may have a fear of doctors because of stories they heard from other people in their communities or may perceive seeing a doctor as in opposition to normal practice. Such attitudes can prevent Appalachians from seeking potentially life-saving screenings and regularly visiting a doctor's office.

> I know that people have a great fear of doctors and sometimes do not go because of that—because someone has told them a story. I have a 62-year-old sister who has never had a female exam. Not breast or anything else. That's because my mother, after she had her last child, she didn't go to the doctor for 40 years.

Cancer continuum: Stories that relayed cancer experiences spanned the cancer continuum from etiology to end of life. One predominant aspect reflected participants' perceptions of cancer causes. In particular, the stories signaled an ongoing debate about gene-environment interaction. Many participants believed that "cancer was more a hereditary thing" because of a devastating family history of the disease. Heritage consistently was mentioned in cancer stories, whether familial or mountain community (e.g., coal mining as a causal agent). Participants offered narratives rooted in confusion and anger that ultimately suggested a love-hate relationship with industries that were part of their pasts. Virginia and Tennessee participants identified their homes—the mountains—as actually holding in the pollution from local industries.

> I've always heard about all this because we are in the mountains. The stuff that makes them smoky and holds everything down, and I've heard particularly older people say that too . . . that the mountains kind of hold things in.

Metaphorically, the mountains also seem to hold in culturally bound stories about the ubiquitous nature of cancer and, especially, the causes of cancer.

Cancer Collectivism

The cancer experience in some Appalachian communities, including the consequences, is perceived to affect everyone, particularly families. Because of geographic and economic barriers, rural families and communities tend to rely on themselves. This can create the need to be loyal to specific social groups, especially families, and thereby subordinate personal needs to group needs. One participant eloquently stated the following in regard to underuse of cancer screening.

> Most of this, whether it's lack of information [or] lack of treatment . . . [is] the inability to even think beyond. They are surviving day to day. They don't have time to think about whether they're going to survive five years from now. So they put [going to the doctor] off. That's just one more trouble they don't need to work with. They need to feed the baby tomorrow.

Ultimately, cancer screening and prevention were not necessarily framed as selfless or important for the family; rather,

participants often characterized meeting immediate needs as the most family-oriented actions Appalichians could take.

Healthcare Challenges

In general, participants appeared doubtful about their ability to access, navigate, or even trust the healthcare system. Moreover, perceptions of being "invisible" may aggravate their already tenuous relationship with the healthcare system.

Healthcare system fatalism: Throughout the work group sessions, a sense of pessimism appeared to exist regarding Appalachians' place in the healthcare system. Some participants said that Appalachians are regarded as "second-class citizens," especially in relation to health care. One work group member remarked, "In Appalachia, we are . . . last to get anything: medical tests, MRIs [magnetic resonance imaging], the good doctors."

Work group members identified three major healthcare system challenges: fatalism, navigation, and patient-provider trust. A substantial portion of rural Appalachia's population is uninsured or underinsured, resulting in a fatalistic attitude toward their ability to access the healthcare system. Participants also discussed the challenge of navigating the system once patients accessed it. As one participant said about his personal experiences with the local healthcare system, "The most frustrating thing for me . . . is the right hand not knowing what the left hand is doing." Similarly, another participant described a scenario about patients in her community.

Here they go into the big hospital, and they are shuffled around, given papers; I've seen it happen, you know. "You go do this. You go do that." There's not really an advocate—somebody that is going to take the time and explain to them.

Successful healthcare interactions generally involve having a trusting relationship between the provider and patient; however, stories about contradictory information and fear of the provider can erode trust at the community level. For example, one participant said, "You hear a lot of talk in this area about, 'Well, I went to that doctor and the doctor did me no good,' or 'That doctor let my momma die.'" This distrust may be heightened by the perceived lack of a personal connection between Appalachian patients and their providers. For example, several participants expressed frustration at being rushed by their overscheduled providers as well as having to interact with providers who had to be reminded repeatedly by patients about their medical histories.

Appalachian invisibility: Work group members also voiced considerable anger about state governments' history of overlooking Appalachia. As one participant said, "[They] don't even know that we even exist." Another added, "I think the legislative body and our government and state has sort of forgotten about us." Participants seemed to tie a sense of invisibility into persisting overgeneralizations about poverty throughout the region.

We've had such bad press from some of the things that have happened here over the years. People come in here from Washington or places and they don't see the good things about the area. They mostly pick out the poverty and language and the fact that we are coal mining and how bad it looks in places . . . that's all that people see about our area.

The perception of being invisible appeared to be made worse by Appalachians' lack of knowledge of the existence of their respective states' comprehensive cancer control plans. Both work groups expressed anger and concern that such plans existed but that their Appalachian communities had not been consulted on the creation or implementation of the plans.

Cancer Expectations

Some Appalachian communities may have low expectations of cancer care provided in healthcare systems. As a result of the characteristics outlined previously, some rural Appalachians may not yet embrace what others see as basic patient rights. Work group members frequently described a sense of despondency in their communities, especially regarding the standard of care for cancer screening, diagnosis, and treatment.

A lot of people don't realize the standard of care that the doctor and healthcare provider is obligated to provide. Take charge of your own health—it's rarely done around here. So, I don't think our community knows the standard of care that our providers should give us. So therefore, we cannot say, "Did you check this?"

Preferred cancer uncertainty and cancer avoidance: Low expectations of some Appalachians regarding cancer-care appear to engender a preference toward remaining uncertain about their cancer status. Work group members reported that individuals in their communities often opted to live "in the dark" when it came to cancer.

A lady I work with has tumors . . . maybe cervical cancer, and her doctor's appointment last Friday got cancelled. And she came back and went, "Well I'm glad." And I said, "What are you talking about? You're glad you know that your appointment was cancelled?" And she was actually afraid of what they were going to find. And I think a lot of people are thinking, "If I ignore it, it will go away."

A consequence of a preference for uncertainty is cancer avoidance. Although some access-related barriers underlie avoidance, people living in Appalachia may not "want to have to deal with" cancer. One work group member discussed the fear that often underlies avoidance. "Rather than facing and saying, 'the sooner something is found the sooner something can be done,' a lot of it is fear. . . . So they tend not to go [for screening]." Cancer avoidance may be the result, in part, of the "hectic and hurried" lives of Appalachians, especially because of the tight bonds of families and other social groups.

One thing is the trouble to getting to [screening], 'cause they are always held during working hours, and so if they are working, they got to be on the job. They can't take that time off. And some of it is just immediate needs. They don't perceive it as an immediate need unless there is a history of it, some sort of, something happens, "Well I have got to go in and get checked." . . . We can't even get them there to take their kids for checkups to get them into school. It's hard enough to get them to do that, let alone get them in for themselves when they're not sick.

Cancer avoidance appears to be linked with cancer collectivism in that some Appalachians prefer to remain uncertain about the presence (or absence) of cancer—particularly if cancer is asymptomatic—rather than inconvenience their families or interfere with their hectic schedules.

Discussion

The study was the first to explore cancer research review work groups as an innovative approach to obtaining community leaders' perspectives about cancer in Appalachia. Work group participants most notably reported (a) cancer storytelling among familial and social networks in regional communities, (b) cancer collectivism or the concept of placing the needs of the family or community before personal cancer screening needs, (c) healthcare system fatalism related to access to care, navigating the healthcare system, and patient-provider trust issues as well as feelings of invisibility and anger relative to the perceived lack of presence in state cancer control plans, and (d) low cancer care expectations and a preference for cancer uncertainty and cancer avoidance.

The findings underscored existing literature about the role of storytelling in Appalachia. Some scholars argue that "the combination of geographic isolation and tight family and community ties fostered a culture of storytelling" in parts of Appalachia (Olson, 1998, p. 73). The oral tradition also appears to encompass issues surrounding health and illness.

Because of geographic and economic barriers, rural families and communities may rely on and create loyalties with each other. A recent publication described a similar phenomenon, psychological collectivism (Jackson, Colquitt, Wesson, & Zapata-Phelan, 2006), which describes the preference for and reliance on in-groups (or trusted individuals) and a prioritization of in-group goals over personal goals. The notion of collectivism appears to apply to cancer experiences in Appalachia. Cancer screening, especially when patients are asymptomatic, may not be a high priority because it requires an expenditure of resources (e.g., time, money) that may be better spent on family needs. Perhaps tellingly, what was absent in the work groups' discussions was the expressed belief that individuals have the obligation to keep themselves healthy for their families. Rather, the obligation appeared to be one of helping the family survive the challenges of living in rural Appalachia.

Findings challenge the beliefs that Appalachians are, in general, a fatalistic people and, in particular, a people fatalistic about cancer. More than 40 years ago, the first edition of Jack Weller's (1993) book *Yesterday's People: Life in Contemporary Appalachia* was published. In his book, Weller argued that the "harshness of the land" had given rise to a "fatalistic attitude" (p. 37). Weller's characterizations in his best-selling book may have helped to convince several generations of readers of the general pessimism of Appalachians. Not surprisingly, subsequent research has continued to describe Appalachian patients as fatalistic, thus failing to capture the true diversity in the region.

Something akin to cancer optimism was apparent in the data. Both work groups indicated that a traditional subculture in Appalachia believed that cancer and cancer treatment were always fatal; however, work groups also claimed that faith emerged in their communities regarding cancer screening and treatment opportunities and an unwillingness to give up on family members with cancer. In fact, several cancer survivors in the group openly disclosed their own cancer experiences, stating that their existence was evidence that Appalachians could and did survive cancer. If a link between poverty and cancer fatalism does exist, as Powe and Finnie (2003) discussed in their extensive review of cancer fatalism research, evidence of cancer fatalism may continue to decline as Appalachia's economies strengthen.

Although findings did not indicate that cancer fatalism is a pervasive paradigm in Appalachia, work groups still identified the existence of pessimism in their communities. The pessimism centered on perceptions of a healthcare system that was broken and uncaring. The term "fatalism" as it is used in the study captures a frustration that goes beyond cultural roots. The broken healthcare system is tied to economic and structural realities (i.e., underinsured, overburdened, and underserved healthcare organizations); hence, it may be more appropriate to describe the community perceptions about their healthcare system as realistic as opposed to fatalistic.

Finally, whereas cancer optimism may be budding in rural Appalachia, a resistance to pursuing cancer screening assertively still exists. Competing life priorities (relative to economic hardship) and a sense of fatalism toward the healthcare system may serve as obstacles; thus, some Appalachians may choose cancer uncertainty or avoidance over screening. The findings are similar to other research on special populations. For example, in their qualitative research on people living with HIV or AIDS, Brashers et al. (2000) and Brashers, Neidig, and Goldsmith (2004) found that people sometimes prefer to remain uncertain about their illness—real or potential—especially when that illness brings with it life-altering consequences. In the present research, however, the preference of uncertainty appeared to have more to do with the potential impact of cancer screening or a cancer diagnosis on the family as opposed to an individual's stigmatization within the community or the fear of death.

Limitations

The study primarily was limited by a lack of diversity among participants. The vast majority of work group members were white, middle-class English speakers with high motivation for participation in research. As recognized by several work group members, certain integral subpopulations of Appalachia were not involved in the project, including those who might be the most economically and socially disadvantaged in the region. It may be telling that primarily middle-class people could take time to participate in a time-consuming research project. Arguably, the participants still were important vessels for their communities, helping voice stories, perceptions, histories, and values. All work group participants also had an inherent interest in cancer that likely contributed to their motivation to participate. Despite those limitations, consideration of the findings as impetus for future research is warranted.

Implications for Practitioners

Throughout the five sequential sessions, group facilitators asked work group members to share any advice they had related to improving cancer care in the community and partnering with the academic community to help bridge the cancer disparities gap. Work group members underscored the importance of appreciating communities' cancer stories. The technique of asking for advice was used successfully in prior studies to increase experiential depth on the part of the researcher (Hutson & Alter, 2006).

Work group participants suggested patient navigator and advocate services, the use of cultural interpreters to reach communities, and patient-provider communication. The vital role of advocates such as lay health advisors has become increasingly recognized as a means of bridging the gap between the healthcare system and lay people (Anderson,

2004; Hinton, Downey, Lisovicz, Mayfield-Johnson, & White-Johnson, 2005). The recognition was not lost on work group participants, who explicitly discussed the important functions of patient liaisons to assist with "interpreting" confusing medical terminology and navigating the bureaucracy of the healthcare system. In a region where many communities face a shortage of healthcare professionals and a lower level of educational attainment, such advocates could improve patient-provider communication; this was one of the most common recommendations from both work groups.

Work group participants also discussed the importance of using established cultural insiders, specifically community leaders (e.g., church ministers, leaders of social organizations, parish nurses), to serve as liaisons between healthcare professionals or researchers and the community. The suggestion reinforces the idea that to communicate effectively and partner with disparate populations, healthcare professionals must involve credible in-group members (Dorgan, Hutson, & Phillips, 2007). Work group members also advised that researchers and healthcare professionals become involved at local community-based events.

Work group members specifically suggested tailoring cancer information to individual patients' attributes (e.g., educational and literacy level, cultural and familial beliefs). The notion is nothing new in health care; the message from work group members helps to sustain the importance of communication as one of the most influential factors in improving patient-provider rapport.

Conclusions

The rich descriptions gained from 22 grass roots community leaders in northeastern Tennessee and southwestern Virginia with diverse backgrounds, personalities, and life experiences yielded four major themes that make the experience of cancer in Appalachia unique. Moreover, the use of community research review work groups has a distinct advantage—participants can return to their families and communities and serve as highly influential sources of cancer information and support.

The findings from the study provide a unique foundation so that healthcare providers and researchers can address cancer disparities in the Appalachian region. As cancer stories continue to percolate in Appalachian communities, they will shape and reshape individual cancer experiences.

Author Contact: Sadie P. Hutson, PhD, RN, WHNP, can be reached at hutsons@etsu.edu, with copy to editor at ONFEditor@ons.org.

References

Anderson, C.M. (2004). The delivery of health care in faith-based organizations: Parish nurses as promoters of health. *Health Communication, 16,* 117–128.

Appalachian Regional Commission. (n.d.). Appalachian region: Economic overview. Retrieved July 13, 2006, from http://www.arc.gov/index.do?nodeId=26

Appalachian Regional Commission. (2004). Cancer mortality in Appalachia. In *An analysis of disparities in health status and access to health care in the Appalachian region: An ARC report.* Retrieved February 8, 2005, from http://www.arc.gov/index.do?nodeId=2343&print=yes

Armstrong, L.R., Thompson, T., Hall, H.I., Coughlin, S.S., Steele, B., & Rogers, J.D. (2004). Colorectal carcinoma mortality among Appalachian men and women, 1969–1999. *Cancer, 101,* 2851–2858.

Behringer, B. (1994). Health care services in Appalachia. In R.A. Couto, N.K. Simpson, & G. Harris (Eds.), *Sowing seeds in the mountains: Community-based coalitions for cancer prevention and control* (pp. 62–80). Washington, DC: National Institutes of Health and National Cancer Institute.

Behringer, B., & Friedell, G.H. (2006). Appalachia: Where place matters in health. *Preventing Chronic Disease, 3,* A113. Retrieved October 3, 2007, from http://www.cdc.gov/Pcd/issues/2006/oct/06_0067.htm

Billings, D.B. (2006). Welfare and poverty. In R. Ambramson & J. Haskell (Eds.), *Encyclopedia of Appalachia (*pp. 236–237). Knoxville, TN: University of Tennessee Press.

Bluegrass Coalition for Cancer Screening & Kentucky Medical Association Cancer Committee. (2005). Colorectal cancer facts. *Journal of the Kentucky Medical Association, 103,* 118.

Brashers, D.E., Neidig, J.L., Haas, S.M., Dobbs, L.K., Cardillo, L.W., & Russell, J.A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs, 67,* 63–84.

Brashers, D.E., Neidig, J.L., & Goldsmith, D.J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16,* 305–331.

Butterfoss, F.D., Goodman, R.M., & Wandersman, A. (1993). Community coalitions for prevention and health promotion. *Health Education Research, 8,* 315–330.

Coughlin, S.S., Costanza, M.E., Fernandez, M.E., Glanz, K., Lee, J.W., Smith, S.A., et al. (2006). CDC-funded intervention research aimed at promoting colorectal cancer screening in communities. *Cancer, 107,* 1196–1204.

Couto, R.A., Simpson, N.K., & Harris, G. (Eds.). (1994). *Sowing seeds in the mountains: Community-based coalitions for cancer prevention and control.* Rockville, MD: National Cancer Institute.

Cunningham, J.E., & Butler, W.M. (2004). Racial disparities in female breast cancer in South Carolina: Clinical evidence for a biological basis. *Breast Cancer Research and Treatment, 86,* 161–176.

Denham, S.A., Meyer, M.G., Toborg, M.A., & Mande, M.J. (2004). Providing health education to Appalachia populations. *Holistic Nursing Practice, 18,* 293–301.

Dorgan, K.A., Hutson, S.P., & Phillips, A. (2007). [In]Credible agents: Cancer communication partners in Appalachia. *Business Research Yearbook, 14,* 597–602.

Fouad, M.N., Nagy, M.C., Johnson, R.E., Wynn, T.A., Partridge, E.E., & Dignan, M. (2004). The development of a community action plan to reduce breast and cervical cancer disparities between African-American and white women. *Ethnicity and Disease, 14*(3, Suppl. 1), S53–S60.

Friedell, G.H., Linville, L.H., Rubio, A., Wagner, W.D., & Tucker, T.C. (1997). What providers should know about community cancer control. *Cancer Practice, 5,* 367–374.

Friedell, G.H., Rubio, A., & Harris, G. (1994). *Central Highlands Appalachia Leadership Initiative on Cancer: Sowing seeds in the mountains.* Washington, DC: National Institutes of Health and National Cancer Institute.

Friedell, G.H., Rubio, A., Maretzki, A., Garland, B., Brown, P., Crane, M., et al. (2001). Community cancer control in a rural, underserved population: The Appalachian Leadership Initiative on Cancer Project. *Journal of Health Care for the Poor and Underserved, 12*(1), 5–19.

Green, L.W., & Mercer, S.L. (2001). Can public health researchers and agencies reconcile the push for funding bodies and the pull from communities? *Journal of Public Health, 91,* 1926–1929.

Halverson, J.A., Barnett, E., & Casper, M. (2002). Geographic disparities in heart disease and stroke mortality among black and white populations in the Appalachian region. *Ethnicity and Disease, 12*(4, Suppl. 3), 82–91.

Heckler, M.M. (1985). *Report of the secretary's task force on black and minority health.* Washington, DC: U.S. Government Printing Office.

Henschke, U.K., Leffall, L.D., Mason, C.H., Reinhold, A.W., Schneider, R.L., & White, J.E. (1973). Alarming increase of the cancer mortality in the U.S. black population (1950–1967). *Cancer, 31,* 763–768.

Hinton, A., Downey, J., Lisovicz, N., Mayfield-Johnson, S., & White-Johnson, F. (2005). The community health advisor program and the deep South network for cancer control: Health promotion programs for volunteer community health advisors. *Family Community Health, 28*(1), 20–27.

Huang, B. (2002, June). Cancer death rates—Appalachia, 1994–1998. *Morbidity and Mortality Weekly Report, 51,* 527–529.

Hutson, S.P., & Alter, B.A. (2006). The experiences of siblings of patients with Fanconi's anemia. *Pediatric Blood and Cancer, 48,* 72–79.

Huttlinger, K., Schaller-Ayers, J., & Lawson, T. (2004). Health care in Appalachia: A population-based approach. *Public Health Nursing, 21,* 103–110.

Israel, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (2005). *Methods in community-based participatory research for health*. Jossey-Bass: San Francisco, CA.

Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19,* 173–202.

Isserman, A. (1996). *Appalachia then and now: An update of "The Realities of Deprivation" reported to the president in 1964*. Retrieved June 8, 2007, from http://www.arc.gov/images/reports/thenandnow/then.pdf

Jackson, C.L., Colquitt, J.A., Wesson, M.J., & Zapata-Phelan, C.P. (2006). Psychological collectivism: A measurement validation and linkage to group member performance. *Journal of Applied Psychology, 91,* 884–899.

Kephart, H. (2000). *Our southern highlanders: A narrative of adventure in the southern Appalachians and a study of life among the mountaineers.* Knoxville, TN: University of Tennessee Press.

Lengerich, E.J., Tucker, T.C., Powell, R.K., Colsher, P., Lehman, E., Ward, A.J., et al. (2005). Cancer incidence in Kentucky, Pennsylvania, and West Virginia: Disparities in Appalachia. *Journal of Rural Health, 21,* 39–47.

Mulcahy, R.P. (2006). Health. In R. Ambramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 1631–1677). Knoxville, TN: University of Tennessee Press.

National Institutes of Health. (n.d.). What are health disparities? Retrieved June 14, 2007, from http://healthdisparities.nih.gov/whatare.html

Neuendorf, K.A. (2002). *The content analysis guidebook.* Thousand Oaks, CA: Sage.

Office of Disease Prevention and Health Promotion. (n.d.). Healthy people 2010. Retrieved February 8, 2007, from http://www.healthypeople.gov

Olson, T. (1998). *Blue Ridge folklife*. Jackson, MS: University of Mississippi Press.

Orslene, L.E. (2006). New deal communities. In R. Ambramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 186–189). Knoxville, TN: University of Tennessee Press.

Polednak, A.P. (2004). Racial differences in mortality from obesity-related chronic diseases in US women diagnosed with breast cancer. *Ethnicity and Disease, 14,* 463–468.

Powe, B.D., & Finnie, R. (2003). Cancer fatalism: The state of the science. *Cancer Nursing, 26,* 454–465.

Rural Appalachian Cancer Demonstration Program. (n.d.). History of the project. Retrieved June 14, 2007, from http://www.etsu.edu/kellogg/racdphomw.htm

Wallerstein, N.B., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7,* 312–323.

Weller, J. (1993). *Yesterday's people: Life in contemporary Appalachia.* Lexington, KY: University Press of Kentucky.

Williams, J.A. (2002). *Appalachia: A history.* Chapel Hill, NC: University of North Carolina Press.

Yabroff, K.R., Lawrence, W.F., King, J.C., Mangan, P., Washington, K.S., Yi, B., et al. (2005). Geographic disparities in cervical cancer mortality: What are the roles of risk factor prevalence, screening, and use of recommended treatment? *Journal of Rural Health, 21,* 149–157.