Published in final edited form as:

Qual Health Res. 2007 January ; 17(1): 131–141. doi:10.1177/1049732306296507.

Key Informants' Perspectives Prior to Beginning a Cervical Cancer Study in Ohio Appalachia

Mira L. Katz,

The Ohio State University

Mary Ellen Wewers,

The Ohio State University

Nancy Single, and

American Cancer Society

Electra D. Paskett

The Ohio State University

Abstract

Higher-than-average cervical cancer incidence and mortality rates occur in Ohio Appalachia. Little is known, however, about societal norms and social determinants that affect these rates. To examine county-level sociocultural environments to plan a cervical cancer prevention program, the authors interviewed key informants from 17 of 29 Ohio Appalachia counties. Findings include the perceived offensiveness of the term Appalachia, the importance of long-standing family ties, urban and rural areas within counties, use and acceptability of tobacco, the view that cancer is a death sentence, and the stigmatization of people with cancer. Barriers to screening included cost, lack of insurance, transportation problems, fear, embarrassment, and privacy issues. These findings highlight the important role of geography, social environment, and culture on health behaviors and health outcomes. The interviews provided information about the unique characteristics of this population that are important when developing effective strategies to address cancer-related health behaviors in this medically underserved population.

Keywords

cervical cancer; Appalachia; cancer prevention; cancer screening

The introduction and adoption of the Papanicolaou (Pap) smear to prevent cervical cancer has significantly reduced the incidence and mortality of this disease in Westernized countries since the 1950s (Moritz, Farber, Bristow, & Cornelison, 2001; Munoz & Bosch,

© 2007 Sage Publications

Mira L. Katz, PhD, MPH, is an assistant professor in the Division of Health Behavior and Health Promotion, School of Public Health, and the Comprehensive Cancer Center, The Ohio State University, Columbus.

Mary Ellen Wewers, PhD, is a professor in the Division of Health Behavior and Health Promotion, School of Public Health, and the Comprehensive Cancer Center, The Ohio State University, Columbus.

Nancy Single, PhD, is a researcher at the American Cancer Society, Atlanta, Georgia.

Electra D. Paskett, PhD, is a professor in the Division of Epidemiology, School of Public Health, and the Comprehensive Cancer Center, The Ohio State University, Columbus.

1992). Still, it is estimated that in 2006, more than 9,700 women in the United States will be diagnosed with invasive cervical cancer, and 3,700 women will die from this cancer (American Cancer Society, 2006). These cases are all preventable if regular Pap smear screening and appropriate treatment for abnormalities occur (Blackman, Bennett, & Miller, 1999; Jemal et al., 2005).

High rates of cervical cancer are due, in general, to (a) high prevalence of risk factors for cervical cancer, (b) low rates of screening, (c) absence of proper and timely follow-up for abnormalities identified through screening, and (d) survival differences due to lack of appropriate treatment (Leyden et al., 2005; Newmann & Garner, 2005; Wewers et al., 2000; Yabroff et al., 2005). Each of these reasons for increased cervical cancer rates might be influenced by multiple factors. For example, the social environment (poor access to health care, inadequate transportation options, lack of child care), health behaviors (tobacco use, sexual activity), work (environmental exposures), pathophysiological changes (human papillomavirus; HPV), or an individual's culture (values, beliefs, attitudes) might either exacerbate or mediate the problem.

On average, screening rates for cervical cancer are high in the United States; however, certain segments of the population have not benefited equally from the availability of screening. Specifically, older women, those with lower income, recent immigrants, and minority women continue to have lower-than-average cancer-screening rates and experience greater morbidity and mortality from cervical cancer, as do those who live in rural or geographically isolated areas, such as Appalachia (American Cancer Society, 2005; Centers for Disease Control and Protection [CDC], 2002; Friedell et al., 1992; Hall, Rogers, Weir, Miller, & Uhler, 2000; Lengerich et al., 2005; Yabroff et al., 2005). Between 1996 and 2000, the cervical cancer incidence rate for Ohio was 9.2 per 100,000 women, slightly lower than the cervical cancer incidence rate of 9.6 per 100,000 women for the United States (Ohio Cancer Incidence Surveillance System, 2003). Rates within Ohio vary by county, however, with many Ohio Appalachia counties reporting incidence rates that are higher than the U.S. rate (11.4 to 20.3 per 100,000 women; Ohio Cancer Incidence Surveillance System, 2003).

Reasons why women living in Ohio Appalachia experience increased cervical cancer morbidity and mortality rates involve factors beyond the level of an individual's health. The Social Determinants of Health (SDH) Framework is a theoretical framework that focuses on the influences that social and cultural environments have on health (Marmot & Wilkinson, 1999). Thus, what influences an individual's health, in addition to biology, includes material circumstances, social and work environments, health behaviors, early life experiences, and culture.

To gain insight into how these factors are perceived at the county level among women living in Ohio Appalachia, we used the well-recognized method of in-depth face-to-face interviews with key informants prior to designing a cervical cancer prevention intervention program (Rissel & Bracht, 1999). Using this method, we were able to explore information about cancer-related issues at the county level from individuals within the community who were knowledgeable about these specific issues and who could provide insight into the behavioral

motivations in this population, which is essential for developing effective educational programs.

Method

This qualitative study was conducted in conjunction with the Community Awareness, Resources and Education (CARE) Project, one of eight National Institutes of Health (NIH)–funded Centers for Population Health and Health Disparities (National Cancer Institute, 2002). The goal of the CARE Project is to investigate the interaction of environmental, societal, behavioral, and biological mechanisms as they contribute to understanding the causes and prevention of cervical abnormalities in Ohio Appalachia. The CARE Project consists of three interrelated research studies. One study focuses on increasing Pap smear use, the second addresses smoking cessation, and the third research study focuses on understanding the factors, especially HPV, that cause cervical abnormalities in Ohio Appalachian women.

The CARE Project is set in Ohio Appalachia, an area characterized by high cervical cancer incidence and mortality rates. Using a random selection procedure, 17 counties were selected from the 29 Appalachian Ohio counties to participate in this project. We selected counties by (a) dividing the 29 counties into 4 geographic regions (Figure 1); (b) categorizing each county as urban or rural according to the U.S. Census Bureau,¹ (c) grouping counties where health care was limited with a contiguous county where more care was available, and (d) randomly sampling two counties (or county pairs) within each region and urban or rural combination, using probability proportional to size based on annual counts of cervical cancer in each county weighted so that counties estimated to have more women at risk were more likely to be selected.

Theoretical Framework

A semistructured, open-ended questionnaire was developed as an interview guide based on the influences on health described in the SDH Framework by Marmot and Wilkinson (1999) (Figure 2). The model proposes that inequalities of the social environment (social capital, neighborhood disadvantage, etc.) are important to consider if we are to have a better insight into health disparities. By understanding specific societal features and local culture, as well as individual health behavior choices, health professionals might be able to develop more effective educational interventions.

Development of the Questionnaire

The interview guide was developed by a team of investigators associated with the CARE Project. Two expert consultants reviewed the interview guide, and the guide was pilot-tested and revised before being used during the key informant interviews. The questions focused on the key constructs of the SDH framework specific to the development of cervical cancer

¹The United States Census Bureau defines an *urbanized area* as consisting of a large central place and adjacent densely settled census blocks that together have a total population of at least 50,000 people. *Urban clusters* have a similar definition; however, the overall population can be 2,500 to less than 50,000. The Census Bureau defines all other areas as rural (see U.S. Census Bureau Web site, <http://www.census.gov>).

as well as cancer-related issues that might be influenced by living in Ohio Appalachia. Questions were grouped into six major categories that addressed the components of the SDH Framework (Table 1): (a) social environment and culture; (b) local business and government; (c) risky behaviors associated with cervical cancer; (d) cancer screening beliefs and attitudes; (e) health care use, access, and trust; and (f) identifying local advocates for cancer prevention and control.

All interviews were conducted by a CARE Project team member after completion of a training session and following approval of the Institutional Review Board of The Ohio State University.

Interviews

Face-to-face interviews were conducted between September and December 2003 with 18 key informants from the 17 Ohio Appalachia counties (9 rural and 8 urban) involved in the CARE Project. These informants were identified by one of the coauthors (NS) and were chosen because of their long-standing residence in the communities, their detailed knowledge about cancer beliefs and prevention efforts in the different counties, the fact that each represented a county-level American Cancer Society office, and their willingness to participate in the interview.

After a scripted brief introduction and verbal consent from the informants, we conducted the interviews by following, in order, the topics and questions in the interview guide. Each interviewer, however, had the discretion to follow leads and probe further following a respondent's answer. The interviews took approximately 90 minutes to complete, allowing sufficient time to discuss the numerous issues associated with each of the six categories listed above. Responses were recorded using detailed field notes. Each interviewer reviewed his or her notes for clarity, and all interviews were then read by two co-investigators and information was displayed in a data matrix. Data were analyzed within each major section of the questionnaire for convergent or divergent responses between the four Ohio Appalachian regions. Although there was variation between interviews, we determined that data saturation had been reached because no new information was emerging within each of the major sections of the questionnaire.

Findings

The following results are from the key informant interviews conducted using the SDH framework. In Tables 2 and 3, we have summarized key informants' responses across the four Ohio Appalachia regions.

Social Environment and Culture

The influences of the social environment and culture are significant factors among the residents of Appalachia. This includes the geographical location (isolation, disadvantage) as well as the historical experiences of the population (social norms, social cohesion, and social networks). For example, the key informants' perception of their counties agreed with the official rural/urban county categorization in 8 of 9 (89%) of the rural counties and in none of

the urban counties. Six of the eight (75%) urban counties were perceived as rural, and three counties (1 rural and 2 urban) were perceived as a mix of both rural and urban.

Residents of the 17 Ohio counties were described as generally White (> 90%), having a high school education or less, having lived in the county most of their lives, and knowing everyone in the surrounding area. The age range of the residents in the different counties was reported as being from the very young to the elderly, and the marital status of the residents varied from long-established unions to an acknowledged increase in divorce rates. Major strengths of living in Ohio Appalachia, according to the key informants, were “the land is beautiful,” “it is a healthier environment,” “there is an absence of crowds,” “it is very quiet,” “reduced crime,” “strong family ties to the land,” and “the advantage of an extended family because everyone knows everyone.” In addition, most informants identified the existence of “hollers,” or isolated areas within each county.

Respondents from all four regions stated that residents did not consider themselves Appalachian. The term *Appalachia* is considered by residents to be offensive, because it is associated with many negative stereotypes (uneducated, toothless, etc.). Most residents prefer to be identified as a resident from Ohio or from a specific Ohio county.

Local Business and Government

The organization of work and work site regulations are also important influences on the health of individuals. Key informants described the current general business conditions in the counties as being limited, with most residents working in hospitals, factories, or small businesses, or farming the land. Key informants from 11 of the 17 counties mentioned that unemployment was on the rise, that residents were being laid off, and “lots of things have closed” with regard to small businesses. Residents’ perspective on tobacco use might be influenced by the fact that tobacco is currently a cash crop in three of the four Ohio Appalachia regions and in eight counties included in this research project (Tobacco Risk Reduction Program, 2004). Tobacco is one of the issues affecting the economy because, as one of the major crops in Ohio Appalachia, pressure has been on the farmers not to grow tobacco, which has translated into less revenue.

Leadership that residents recognized and respected at the county level was evenly divided among local mayors, city council members, and county commissioners. Leaders were thought of as “very qualified,” influential, and supportive of local concerns, including health issues.

Risky Behaviors and Cervical Cancer

Social patterns of risky behaviors might also provide insights into the cervical cancer rates documented among women living in Ohio Appalachia. When asked why they thought cervical cancer rates were increased in Appalachia, key informants from 11 out of 17 counties attributed the increased rates in their counties to risky behaviors. Risky sexual behaviors (early onset of intercourse, multiple partners, etc.) ($n = 10$), inadequate screening rates ($n = 5$), and smoking ($n = 3$) were mentioned by the key informants as possible reasons for increased cervical cancer rates.

Tobacco use was listed as a problem in every county. One key informant stated that many residents smoked, chewed tobacco, or used snuff. Use of tobacco was reported as being on an upswing among youth in most counties, and one individual described that “it is fairly common to see second- and third-grade students smoking or chewing tobacco.” The use of smokeless tobacco was reported as being especially popular among adolescents in several counties. Alcohol abuse was also mentioned as a problem in 11 counties, and its use was mentioned as increasing in 2 other counties. Increased use of alcohol was reported as being directly related to the declining economy in most counties.

Cancer Screening Beliefs and Attitudes

Individual beliefs, values, attitudes, knowledge, fears, and motivation about preventive health behaviors are influenced by various factors categorized under culture and the psychological dimensions of health. When asked to describe the major cancer worries of the residents in their communities, only 1 key informant mentioned cervical cancer. Breast and lung cancer were mentioned as a concern in 14 counties, prostate cancer in 8 counties, colon cancer in 3 counties, skin cancer in 2 counties, and a wide variety (brain, thyroid, etc.) were mentioned for 1 county.

Cultural aspects and the psychological dimensions mentioned by the key informants in association with cervical cancer screening included the fear of cancer ($n = 7$), lack of knowledge about cancer and the screening test ($n = 7$), fear/embarrassment ($n = 3$), and privacy issues ($n = 2$). One individual reported that the residents of their county often traveled to neighboring counties to be screened for cancer because of the fear of being stigmatized if they were seen at the clinic and thought to have cancer. In this region, the diagnosis of cancer was still thought of as a death sentence.

Health Care Access, Use, and Trust

Material factors and the social environment can influence the use of the health care system. When asked to describe the state of medical care in the counties, key informants described it as limited/almost nonexistent/poor in 10 of the 17 counties. Again, availability of care depended on living in a city or town versus a rural region of the county across all four regions of Ohio Appalachia. In 10 of the 17 counties, the key informants felt that the residents trusted local health care providers. Mistrust of the health care system and providers was reported by the key informants in the remaining 7 counties. In 5 of the 7 counties where mistrust was reported, the key informants reported that residents traveled to larger cities in other counties for their medical care. In one county, the hospital staff was not trusted, and in another county, the informant reported that individuals with lower socioeconomic status did not trust the health care system. In addition, the key informants mentioned the more typical access barriers to care, such as costs/lack of proper insurance ($n = 10$) and access/transportation ($n = 8$). The ability of an individual to travel to a health care provider differed between and varied within counties. For example, an individual county might have good roads and public transportation within and near a city or town, but public transportation was not available or was extremely poor in most of the counties. In addition, gravel roads in rural regions made it difficult to access care.

Cancer prevention programs have been held in all 17 counties by national, state, or local agencies and organizations. Tobacco cessation programs were mentioned as the most frequent type of cancer prevention program that had been held in the past and was also currently being held in 13 of the 17 counties. Free cancer screening programs have also been conducted in some counties but were mentioned less often than tobacco cessation and prevention programs.

Local Advocates for Health

Positive health behaviors are influenced by the social environment, social support, and social networks. The identification of local advocates for cancer prevention programs was an important step in the key informant interviews. Groups and individuals listed most often included members of the local health departments, the American Cancer Society, the tobacco coalitions, Appalachian Cancer Network, local government officials, local businesses, radio and television personalities, and local cancer survivors. Key informants reported that these advocates had a strong public presence and were respected in the local communities.

Discussion

The social and environmental influences on a populations' health are often overlooked in the current medical model, which focuses on eliminating disease. This study of key informants from 17 counties in Ohio Appalachia was guided by the Social Determinants of Health Framework in our attempt to address these issues in the development of interventions that might help to lower the cancer rates in this underserved population.

In this study, we identified factors influencing cervical cancer from the perspective of key informants who live in Ohio Appalachia counties. Although the 17 counties had similar cancer-related issues (i.e., increased tobacco use), small differences existed within and between the four designated regions of Ohio Appalachia. Several interesting new issues, however, emerged from this unique focus on how the SDH framework explains cervical cancer rates within a medically underserved population in a specific geographical section of Appalachia.

The first was the unclear distinction between urban and rural counties by the key informants. Within the counties, there appeared to be a mix of urban and rural areas, and the beliefs, attitudes, and experiences of the residents varied depending on where they lived within the county. For example, in one urban county, the key informants reported that the residents of a major city (population of 21,796) had a different perspective on access to health care than the residents who lived in the more remote sections of the county. The urban residents had their choice of physicians, a large and respected hospital, and paved roads, whereas the rural residents usually had a limited number of physicians and emergency care nearby, with dirt roads being common. This is a critical point to recognize when planning community-based cancer prevention programs, as previous research has documented that cancer health disparities are associated with residence in rural areas (Amonkar & Madhavan, 2002; CDC, 2002; Denman, Meyer, Toborg, & Mande, 2004; Gosschalk & Carozza, 2003; Hall, Uhler, Coughlin, & Miller, 2002; Vellozzi, Romans, & Rothenberg, 1996). The differences

between urban and rural life, in addition to societal norms, were discussed during the key informant interviews. These include, but are not limited to, less contact with physicians and preventive care, fewer community services, lack of public transportation, lack of health insurance, and higher rates of poverty in rural areas compared to urban areas. Identification of differences for the six sections of the questionnaire between counties or regions within Ohio Appalachia was not possible because of the mix of urban and rural areas within each county.

A second new issue that emerged was that residents had an aversion to being labeled as “Appalachian” and that many residents preferred to be labeled as being from Ohio or their specific county rather than being called Appalachian. The construction of an Appalachian identity and its exaggerated stereotype as being physically isolated, backwards, and timeless compared to the remaining modern United States has been recorded since the American Civil War (1861–1865) (Algeo, 2003). This descriptive word entails more than a geographic location and to some represents a marker for a culture with disparaging implications. In addition, although there is natural resource wealth in Appalachia, such as coal and timber, the residents of these areas have limited access to these resources (Glasmeier & Farrigan, 2003). The role of stereotypes as boundary markers was also found to be prevalent among higher socioeconomic status residents of Appalachia (Obermiller, 1981).

As in other studies (Lannin et al., 1998; Shell & Tudiver, 2004), the key informants in this study identified the long-standing stigma of having cancer and fatalism as significant barriers for undergoing cancer screening tests for many residents in the Appalachian counties. Furthermore, the residents of many counties were not aware of cancer screening tests, and some residents lacked appreciation of the need to undergo screening because they were asymptomatic. Lack of knowledge and understanding of the importance of cancer screening and this tendency to live with a more present-day orientation has been reported previously among residents of Appalachia (Elnicki, Morris, & Shockcor, 1995; Shell & Tudiver, 2004). Personal cancer-related health behaviors, as well as the social environment, need to change to address the increased cancer incidence and mortality rates in Appalachia Ohio.

This study is significant because of the rigorous sampling method used to select the counties, the theoretical framework used to develop the interview guide, and the fact that key informants from 17 of the 29 Ohio Appalachia counties were interviewed. Several key findings from this study include the perceived offensiveness of the term *Appalachia*, the importance of strong and long-standing family ties, the mix of urban and rural areas within most counties, the wide use and acceptability of tobacco products, the continued view that cancer is a death sentence, and the stigmatization of people with cancer. These unique characteristics of this population are important to keep in mind when developing effective strategies to address cancer-related health behaviors in this medically underserved population. These findings also highlight the important role of geographical location, social environment, and culture on health behaviors and health outcomes.

Information obtained from the interviews was used to develop strategies for a current program designed to address the increased cervical cancer incidence rate in Ohio

Appalachia. Several key informants raised the concern that although women were aware of the Pap test for screening, many did not know about the association between cervical cancer and smoking and/or risky sexual behaviors. Information about these key cervical cancer risk factors, in addition to the importance of completing Pap tests within risk-appropriate screening guidelines, became an integral component of the educational portion of the intervention being delivered to women in need of Pap tests.

It is important to note the limitations of this study. The key informants were residents of the different Ohio Appalachia counties; however, they did not represent the totality of the residents living in the counties. The informants' responses to the questions might have reflected their personal biases associated with their role in the community, their socioeconomic status, or their experiences with health care and illness.

The information reported by the key informants in this study can help health providers to understand the unique features of different Ohio Appalachia residents' beliefs and attitudes about cancer. The key informants in this study reported specific cancer-related beliefs and behaviors that might partially account for the cancer disparities found among residents of Appalachia. To understand current health disparities clearly, components of the Social Determinants of Health Framework must be addressed. Having this type of an accurate community analysis of local culture and concerns, environmental factors, leadership patterns and organizational resources, and access to care issues is essential for designing effective and successful cancer prevention programs at the community level for medically underserved and unique populations. By addressing how the social environment and culture of a population affects health, an opportunity for reducing health disparities in future generations is provided.

Acknowledgments

We represent the investigators of The Ohio State University Center for Population Health and Health Disparities, supported by the National Cancer Institute grant #P50CA105632.

References

- Algeo K. Locals on local color: Imaging identity in Appalachia. *Southern Cultures*. 2003; 9(4):27–54.
- American Cancer Society. Cancer prevention and early detection: Facts and figures, 2005. Atlanta, GA: Author; 2005.
- American Cancer Society. Cancer prevention and early detection: Facts and figures, 2006. Atlanta, GA: Author; 2006.
- Amonkar MM, Madhavan S. Compliance rates and predictors of cancer screening recommendations among Appalachian women. *Journal of Health Care for the Poor and Underserved*. 2003; 13:443–460. [PubMed: 12407962]
- Blackman DK, Bennett EM, Miller DS. Trends in self-reported use of mammograms (1989–1997) and Papanicolaou tests (1991–1997): Behavioral risk factor surveillance system. *Morbidity and Mortality Weekly Report*. 1999; 48(SS-6):1–22.
- Centers for Disease Control (CDC). Cancer death rates—Appalachia, 1994–1998. *Morbidity and Mortality Weekly Report*. 2002; 51(24):527–529. [PubMed: 12088143]
- Denham SA, Meyer MG, Toborg MA, Mande MJ. Providing health education to Appalachia populations. *Holistic Nursing Practice*. 2004; 18(6):293–301. [PubMed: 15624276]

- Elnicki DM, Morris DK, Shockcor WT. Patient-perceived barriers to preventive health care among indigent, rural Appalachian patients. *Archives of Internal Medicine*. 1995; 155(4):421–424. [PubMed: 7848026]
- Friedell GH, Tucker TC, McManmon E, Moser M, Hernandez C, Nadel M. Incidence of dysplasia and carcinoma of the uterine cervix in an Appalachian population. *Journal of the National Cancer Institute*. 1992; 84(13):1030–1032. [PubMed: 1608055]
- Glasmeyer AK, Farrigan TL. Poverty, sustainability, and the culture of despair: Can sustainable development strategies support poverty alleviation in America's most environmentally challenged communities? *Annals of the American Academy*. 2003; 590:131–149.
- Gosschalk, A.; Carozza, S. Cancer in rural areas. In: Gamm, LD.; Hutchinson, LL.; Dabney, BJ.; Dorsey, AM., editors. *Rural Healthy People 2010: A companion document to Healthy People 2010*. Vol. 2. College Station: Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center; 2003. p. v-vi.
- Hall HI, Rogers JD, Weir HK, Miller DS, Uhler RJ. Breast and cervical carcinoma mortality among women in the Appalachian Region of the U.S., 1976–1996. *Cancer*. 2000; 89(7):1593–1602. [PubMed: 11013376]
- Hall HI, Uhler RJ, Coughlin SS, Miller DS. Breast and cervical cancer screening among Appalachian women. *Cancer Epidemiology, Biomarkers, and Prevention*. 2002; 11(1):137–142.
- Jemal A, Murray T, Ward E, Samuels A, Tiwari RC, Ghafoor A, et al. *Cancer Statistics, 2005*. CA—A Cancer Journal for Clinicians. 2005; 55(1):10–30. [PubMed: 15661684]
- Lannin DR, Mathews HF, Mitchell J, Swanson MS, Swanson FH, Edwards MS. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. *Journal of the American Medical Association*. 1998; 279(22):1801–1807. [PubMed: 9628711]
- Lengerich EJ, Tucker TC, Powell RK, Colsher P, Lehman E, Ward AJ, et al. Cancer incidence in Kentucky, Pennsylvania, and West Virginia: Disparities in Appalachia. *Journal of Rural Health*. 2005; 21(1):39–47. [PubMed: 15667008]
- Leyden WA, Manos M, Geiger AM, Weinmann S, Mouchawar J, Bischoff K, et al. Cervical cancer in women with comprehensive health care access: Attributable factors in the screening process. *Journal of the National Cancer Institute*. 2005; 97(9):675–683. [PubMed: 15870438]
- Marmot, M.; Wilkinson, RG., editors. *Social determinants of health*. Oxford, UK: Oxford Press; 1999.
- Moritz F, Farber FL, Bristow RE, Cornelison T. Impact of increasing Papanicolaou test sensitivity and compliance: a modeled cost and outcomes analysis. *Obstetrics and Gynecology*. 2001; 97(5):781–788. [PubMed: 11339934]
- Munoz, H.; Bosch, FX. HPV and cervical neoplasia: Review of case-control and cohort studies. In: Munoz, N.; Bosch, FX.; Shah, KV.; Meheus, A., editors. *The epidemiology of cervical cancer and human papillomavirus*. Lyon, France: Oxford University Press; 1992. p. 251–261.
- National Cancer Institute. Centers for population health and health disparities (RFA: ES-02-009). Washington, DC: Author; 2002 Apr 1.
- Newmann SJ, Garner EO. Social inequities along the cervical cancer continuum: A structured review. *Cancer Causes and Control*. 2005; 16(1):63–70. [PubMed: 15750859]
- Obermiller, PJ. Unpublished doctoral dissertation. Union Graduate School; Cincinnati, Ohio: 1981. Labeling urban Appalachians: The role of stereotypes in the formation of ethnic group identity.
- Ohio Cancer Incidence Surveillance System. *Cervical cancer in Ohio, 1996–2000*. Columbus: Ohio Department of Health; 2003.
- Rissel, C.; Bracht, N. Assessing community needs, resources, and readiness: Building on strengths. In: Bracht, N., editor. *Health promotion at the community level: New advances*. Thousand Oaks, CA: Sage; 1999. p. 59–69.
- Shell R, Tudiver F. Barriers to cancer screening by rural Appalachian primary care providers. *Journal of Rural Health*. 2004; 20(4):368–373. [PubMed: 15551854]
- Tobacco Risk Reduction Program. *Comprehensive tobacco use prevention: Strategic plan 2004–2008*. Columbus: Ohio Department of Health; 2004.
- Vellozzi CJ, Romans M, Rothenberg RB. Delivering breast and cervical cancer screening services to underserved women, Part I: Literature review and telephone survey. *Women's Health Issues*. 1996; 6(2):65–73. [PubMed: 8932459]

- Wewers ME, Ahijevych KL, Chen MS, Dresbach S, Kihm KE, Kuun PA. Tobacco use characteristics among rural Ohio Appalachians. *Journal of Community Health*. 2000; 25(5):377–388. [PubMed: 10982011]
- Yabroff KR, Lawrence WF, King JC, Mangan P, Washington KS, Yi B, et al. Geographic disparities in cervical cancer mortality: What are the roles of risk factor prevalence, screening, and use of recommended treatment? *Journal of Rural Health*. 2005; 21(2):149–157. [PubMed: 15859052]

Figure 1. The Ohio Appalachian Counties Involved in the CARE Project

Note: CARE = Community Awareness, Resources and Education.

Figure 2. Social Determinants of Health Framework Modified for Cervical Cancer in Ohio Appalachia

Table 1

Components of the Social Determinants of Health Framework Included in the Key Informant Questionnaire

Section From Questionnaire	Determinants of Health Framework	Examples of Questions
1. Social environment and culture	Social environment, culture	Do the residents of this county mind being labeled or referred to as "Appalachian" or from "Ohio"? What do you see as the major strengths of this county?
2. Local business and government	Work	Who are the community leaders that citizens recognize and respect? What are the main businesses located in this county?
3. Risky behaviors and cervical cancer	Health behaviors	Do you think that women in your community are more likely to get cervical cancer than women living in other areas of Ohio or the U.S.? Why?
4. Cancer screening beliefs/attitudes	Culture, psychology	Do the residents of this county have any cancer concerns? What keeps people from getting checked or screened for cancer?
5. Health care access, utilization, and trust	Material factors, social environment	What is the availability and/or quality of medical care in this county? Do people trust the health care providers in the county?
6. Advocates for health care	Social environment/social support	What groups are involved in providing cancer prevention and/or tobacco use information? Are there any county leaders or residents who are visible advocates of cancer or tobacco prevention?

Ohio Appalachia Region Comparisons for the CARE Project: Appalachia-Related Issues Reported by Key Informants

CARE Project Regions	Geography	Residents	“Appalachia”	Transportation	Local Business	Health care providers	Quality of available care	Trust of providers
1	Mostly rural	White, high school education, unemployment rates vary	“Appalachian” is offensive and degrading, Ohioan is better	Roads are generally maintained, limited public transportation	Hospitals, manufacturing, farming	Lack of providers and specialists	Limited to good	Varies
2	Mostly rural	White, high school education or less, unemployment rates vary	Half of the population would not like being called “Appalachian”	Roads are generally maintained, no rural public transportation	Hospitals, manufacturing, farming	Lack of specialists and updated technology	Poor to great	Varies
3	Mostly rural	White, high school education, unemployment rates vary	Most do not like term applied to them, county identification is better	Roads are generally maintained (rural roads are not in good condition), limited rural public transportation	Hospitals, manufacturing, farming	Lack of providers	Poor to great	Varies
4	Mostly rural	White, education varies, unemployment rates vary	Term is disliked, better to use Ohioan	Roads are poorly maintained, limited rural public transportation	Hospitals, manufacturing, farming	Lack of providers and services	Mostly good, very limited	Varies

Note: CARE = Community Awareness, Resources and Education.

Table 3

Ohio Appalachia Region Comparisons for the CARE Project: Cancer-Related Issues Reported by Key Informants

CARE Project Regions	Cancer: Top Concerns	Cancer: Screening Awareness	Cancer: Free Screening Programs	Cancer: Screening Behaviors	Cancer: Screening Barriers	Tobacco Use	Local Groups That Provide Cancer Educational Materials/Programs
1	Breast, lung	Varies: limited to high	Varies between counties	Small percent get screened; at hospitals	Fear, privacy issues, lack of awareness, transportation issues, costs	Smoking and smokeless tobacco use is high (especially among adolescents)	American Cancer Society (ACS), health department, hospitals
2	Breast, lung	Varies: limited to high	Yes	Get screened; at hospitals and mobile units	Lack of awareness, costs, transportation issues	Smoking and smokeless tobacco use is high (especially among adolescents)	ACS, health department, hospitals
3	Breast, lung	Varies: limited to high	Yes	Screening behaviors vary	Privacy issues, lack of awareness, costs, transportation issues, fear, fatalistic attitude	Smoking and smokeless tobacco use is very high (especially among adolescents)	ACS, health department, hospitals
4	Breast, lung	Varies: limited to high	Varies between counties	Screening behaviors vary	Privacy issues, transportation issues, fear, costs	Smoking and smokeless tobacco use is very high (especially among adolescents)	ACS, health department, hospitals

Note: CARE = Community Awareness, Resources and Education.