Knowledge, Perceptions, and Attitudes about Cancer among Diverse Rural Appalachian Communities

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RURAL APPALACHIAN CANCER DEMONSTRATION PROGRAM

ABSTRACT

**Background:** Cancer deaths in rural Appalachia exceed national averages; and, cancer is more likely to be diagnosed at later stages. For the first time, this study sought to gain a deeper understanding of knowledge, beliefs, and attitudes about cancer among diverse, rural Appalachians. **Methods:** A qualitative, focus group research design was used to elicit knowledge, beliefs, attitudes, and perceptions about cancer from nine existing diverse, rural, Appalachian groups. **Results:** Knowledge of cancer risks, risk reduction strategies, and screening was low; and, inaccurate and confused knowledge was high for most aspects of cancer across and within all groups. Multiple barriers to cancer screening were reported along with high levels of fatalism. Findings indicate rural Appalachians are not receiving cancer information from their primary health providers and are not engaging in recommended cancer screenings. **Conclusions:** Improving cancer communication, increasing the role of primary care providers in cancer communication and screening, and removing barriers to cancer screening are necessary actions if quality cancer control is to be achieved in rural Appalachia.

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INTRODUCTION

The war on cancer has not equally benefited all Americans.\(^1\) Cancer death rates are higher in certain ethnic and racial populations, in medically underserved areas, and among the poor.\(^2\) Blacks, Hispanics and poor whites are reported to have the heaviest cancer burden in the U.S.\(^3\) For example, the occurrence of prostate cancer is 32 times higher in African American men than white men, and white Appalachian men have the highest lung cancer mortality rates in the U.S.\(^4\) Hispanic women have the highest invasive cervical cancer incidence rates in the U.S., although among white women the highest rates are seen in eastern Kentucky.\(^5\) Like ethnic minority groups, lower socioeconomic populations have higher death rates for most cancers than those in higher socioeconomic levels.\(^6\) Furthermore, cancer incidence is higher and length of cancer survivorship is lower among the American poor.\(^7\)

Cancer incidence and cancer-related mortality rates are higher among poor communities. These communities also experience more problems with cancer treatment, treatment-related side effects, and have a shorter survival period after cancer diagnosis.\(^4,8\) American women in lower socioeconomic areas are diagnosed with breast cancer at more advanced stages, have a higher cancer mortality rate, and use mammography screening less often than women with higher incomes.\(^9-11\)

A special report of the American Cancer Society (ACS) asserts that most, if not all, of the cancer incidence and mortality disparities that exist between racial and ethnic groups are due mainly to socioeconomic status.\(^12\) Baquet et al. found that the increased cancer burden among African Americans in three metropolitan areas was mainly due to the disproportionate distribution of African Americans in the lower socioeconomic levels.\(^13\) Likewise, low screening behavior in Hispanic women has been found to be primarily related to low income and education levels and not ethnicity.\(^14\)

Increasing cancer screening among ethnic minorities and the poor is a major health initiative but, barriers to cancer screening by at risk populations are multifaceted and interwoven. In numerous interviews and focus groups with at risk populations, the ACS found that two of the most critical issues were health care accessibility and insurance.\(^15\)

Knowledge of cancer risk factors and perceptions about cancer survival have been directly linked with cancer screening behavior among women; women with high knowledge levels of cancer risk and accurate perceptions of cancer survival are much more likely to engage in regular screening practices.\(^16\) Likewise, lack of knowledge about screening tests and the benefits of screening have been found to adversely affect cancer screening practices of men.\(^17\) Studies that have explored cancer knowledge levels of Hispanic women have found that higher levels of cancer knowledge translated into higher screening behaviors and vice versa.\(^18,14\)

In a comprehensive literature review, Davis et al. found that health illiteracy is associated with low cancer screening rates, advanced cancer at time of diagnosis,
increased cancer mortality, decreased compliance with a health care plan, and decreased participation in clinical trials. Moreover, people who are functionally illiterate are at greater risk of cancer, have more health problems, are likely to live in poverty, and have lower educational attainment. It is believed that knowledge of cancer screening and symptoms directly impacts what cancer stage is found at time of diagnosis with low cancer knowledge levels correlating with more advanced cancer at diagnosis. “Health literacy” refers to one’s ability to understand health information to the extent of being able to make sound health decisions. Health illiteracy is more likely to be found among the poor; and, those with low health literacy have low levels of accurate cancer knowledge as well as high levels of inaccurate and confused cancer knowledge.

Residents of rural areas have more health problems and also carry a heavier cancer burden. In a large retrospective study designed to investigate differences between rural and urban cancer incidence, researchers found that rural cancer patients are more likely to be diagnosed at advanced stages, have an unstaged malignancy, and have a nonlocalized malignancy at time of diagnosis. Moreover, compared with urban areas, women residing in rural areas are less likely to receive recommended mammograms, clinical breast exams, and Pap tests.

The population of Appalachia is characterized by many of these elements, lending to or associated with elevated cancer incidence and mortality. Appalachia, as defined by the Appalachian Regional Commission, is comprised of 406 counties in 13 states with approximately 23 million people. Although the majority population is white, the Appalachian region actually has a diverse combination of ethnic and racial groups. Approximately 42% of the population is rural compared with 20% of the national population. Central Appalachia, in particular, has the highest sustained poverty rates in the country and a low level of educational attainment. Our investigation was focused in central Appalachia. Overall, the Appalachian population is poorer, less-educated, older, and has less health insurance compared to the rest of the nation.

METHOD

A qualitative, focus group research design was used to elicit knowledge, beliefs, attitudes, and perceptions from nine rural, central Appalachian groups in Eastern Kentucky, Northeast Tennessee, and Southwest Virginia. All nine counties from which the groups were selected have higher age-adjusted cancer mortality rates, higher lung cancer death rates, and, except for one, higher poverty rates when compared with national averages. When compared with national averages, five counties have higher breast cancer death rates, four have higher colorectal cancer death rates, and three have higher prostate cancer death rates (Table 1). Four types of cancers (breast, colorectal, lung, and prostate) were selected for this study on the basis of their prevalence in the region.

A focus group approach to data collection was used to promote community involvement in this participatory study using traditional qualitative standards.
Researchers recruited existing social groups to voluntarily reflect and share community knowledge about cancer. Groups with members whose knowledge may already exceed that of the community because of their training as health professionals were excluded. Facilitator and recorder teams were contracted in each of the three states. A full day training program was provided by researchers for the facilitator-recorder teams to assure continuity of methods and recording among the nine rural community focus groups. The research purposefully tapped into existing social groups that would normally share common knowledge and experiences that would frame the context of public understanding of cancer in their community. Involving communities in defining their collective and individual members’ understanding about health issues like cancer is a methodology being increasingly used particularly about those issues being perceived as personal or public problems as well as the importance of community influence on knowledge, attitudes and behaviors.

Each group was asked to discuss one type of cancer appropriate to the corresponding group’s predominant gender, ethnic, and/or age makeup. The groups and the cancers they discussed included: African American female (1) (breast), African American male (1) (prostate), white male (1) (prostate), white female (1) (lung), Hispanic female (1) (breast), and white, mixed gender groups (4) (colorectal, lung). Of the 79 participants in the nine groups, most were female (70%), white (72%), and older than 59 years of age (63%) (Table 2). Twenty-five percent of the participants had less than a high school diploma and 63% were either HS graduates or had attended college. All groups’ participants, except one group, were long-term residents (>10 years) of their communities.

The unit of analysis for the study was community groups, not individuals. The focus group methodology was chosen as efficient and suitable to identify shared knowledge and beliefs in the selected rural communities. Focus groups provide a useful method in generating a group sense in response to questions as well as being an effective way to explore issues in depth. Data collection from different focus groups allowed identification of commonalities of group responses across different types of cancers as well as the opportunity to compare and contrast responses across groups with different gender, racial, and/or age characteristics. The findings of this study are designed to be useful as part of much broader community participatory research approach to help communities and researchers frame future research questions and cancer issues.

A Cancer Care Continuum was developed by the investigators as a framework to organize the questions posed and collect data from all the focus groups. The Cancer Care Continuum (adapted from Friedell et al.) mirrors the conceptual framework for disease prevention and control that includes primary, secondary, and tertiary health care. The Continuum begins with risks of the disease and proceeds through ten incremental phases to the end of life care. For all phases of the Continuum and for each cancer, a comprehensive literature search was conducted to identify the most current and accurate information for each phase. This allowed each response received during the group meetings (i.e. knowledge, risk factors, risk reduction strategies,
screening, etc.) to be compared then classified as “accurate,” “inaccurate,” or “confused” during data analysis. The investigators agreed upon this strict interpretation of knowledge responses as a preliminary means of identifying major knowledge gaps and confusion. Further analyses were then conducted to capture deeper, more useful explanations and interpretations of the inaccuracies, confusion, and beliefs.

Professional facilitators and recorders were hired and trained to conduct the focus groups and record comments. Pre-meeting training was provided for all facilitators and recorders to introduce the Continuum of Cancer Care model and to assure consistency among the facilitators and recorders. The facilitators used predetermined questions in focus group discussions to encourage sharing of knowledge and attitudes for the type of cancer at each phase of the Continuum. The Continuum also served as a framework for collection, categorization, and analysis of data (Table 3). For each contribution made by individuals within the group, the facilitators encouraged discussion of differences as well as group consensus about details. Group responses were noted on flip charts by the facilitator while the recorder used data collection instruments to check off all knowledge responses given by the group. Additionally, the recorder noted verbatim statements that reflected attitudes and beliefs. Audio tape recording was not used due to potential negative effects of hindering full disclosure by participants.

Two meetings were scheduled with each focus group for the purpose of collecting data. A few groups required only one meeting for data collection rather than two. A final meeting with each group was conducted by one of the physician investigators to answer questions and clarify misperceptions about cancer and cancer care. All meetings for each group were conducted within a three week time period to ensure continuity of participants.

Data from the focus groups were reviewed by the lead author who also conducted a week-long data interpretation and analysis meeting with all facilitators and recorders. The meeting assisted in assuring internal consistency of interpretation of data with multiple levels of data analysis being conducted by members of the research team, the facilitators, recorders, and a qualitative research expert. As part of the week-long data interpretation meeting, results from each of the nine groups were analyzed for accuracy, inaccuracy, confusion, and patterns. Several overarching themes emerged from the analysis meeting.

The investigators obtained IRB exempt approval from East Tennessee State University, Veteran’s Affairs Medical Center, University of Kentucky, and Virginia Department of Health. While participants were informed of the study’s purposes and assured of anonymity, no individual informed consents were obtained or required because data were only gathered at the group level.
RESULTS

General knowledge of the four types of cancer (breast, colorectal, lung, and prostate) was low across the groups and the continua; however, knowledge levels varied among groups, among cancers, and among categories of the Continua. Groups were most knowledgeable of cancer symptoms and least knowledgeable of cancer risk factors. Inaccurate knowledge was greater in frequency than accurate knowledge and confused knowledge was dominant. Neither of the colorectal groups identified change in bowel habits as a symptom of colorectal cancer. Other examples of inaccurate knowledge of cancer symptoms are displayed in Table 4.

Confused knowledge was evident in all groups. Many responses were phrased as questions indicating uncertainty. Responses provided for one type of cancer were actually correct for another type of cancer. For example, “don’t smoke” was given as a risk reducer for breast cancer, and “blood in stool” was given as a symptom of prostate cancer. Participants were frequently confused about dietary factors and cancer. Responses such as “either low fat or high fiber” were frequent when giving risk factors for several cancers discussed.

The participants reported negative perceptions of health care quality and access. Despite available health care in the groups’ geographic areas, a major barrier to obtaining cancer care was the reported inaccessibility of quality care. Participants reported “long waits” or “not able to get doctors appointment” and expressed frustration in navigating a complicated health care system. Lack of insurance was reported as a major barrier to cancer control services for all groups. Statements such as “don’t have enough insurance” and “no money to pay for it” were reported frequently by the participants when discussing cancer screening and treatments. Other barriers to health/cancer care were lack of centralized care (“too many places to go”), lack of transportation, and lack of understanding of insurance matters.

The groups generally reported fatalistic attitudes about cancer and cancer treatments. Statements such as “what’s the use [of cancer screening] you’re going to die anyway” and “it’s [cancer] a death sentence” were typical responses in most groups when discussing risks, risk reduction, and screening. The groups in this study viewed cancer as a fatal disease and did not differentiate cancer that was detected early (and thus highly treatable) from advanced cancer.

The groups were questioned about their knowledge and beliefs of cancer clinical trials. The most frequent response by the participants compared clinical trials to “guinea pig” experiments. The participants acknowledged their lack of understanding of clinical trials and viewed them as risky experiments that may be beneficial “when all else fails.” When asked if they would consider participating in such a trial, the overwhelming response was “no.”

The main source of cancer/health information for the participants was “other” people, including family, friends, and other personal contacts, followed by “TV,”
“magazines,” “Internet,” “health departments/health fairs,” and “physicians” respectively. This finding coincided with negative personal experiences with cancer. For example, when asked about the needs of a cancer survivor, one woman stated “I don’t know any survivors.” In another group, one participant said that all the people in her family had died of cancer. Cancer treatment discussed by the participants in the context of others’ experiences, were also framed in a negative tone such as “the radiation stopped his heart” and “the [cancer] treatment alone will kill you.”

Work, home, and community environmental factors were perceived as cancer risks by most groups. Many participants perceived a “high cancer incidence” in their community as linked to “air pollution,” “coal mine smoke,” “coal dust,” “chemicals,” “slate dumps,” “what you breathe in the workplace,” and/or “pesticides.” Additionally, several participants reported beliefs that “hormones in the meat,” “chemicals on food sources,” and “antibiotics in meat” were causes of cancer.

Main themes drawn from all nine focus groups are seen in Table 5. Investigators chose to use a fairly strict interpretation when classifying the data. A more relaxed interpretation could perhaps have improved the “accurate knowledge” levels but would not influence the levels of “inaccurate” or “confused” knowledge.

DISCUSSION

The cancer burden in rural Appalachia is well documented. Since early detection of cancer often depends on symptom recognition by the patient, incorrect and/or lack of knowledge of symptoms by these group participants might partially explain why cancer is too often first discovered in advanced stages in rural Appalachia and why cancer death rates exceed national averages. Moreover, it is not likely that lifestyle behavior will be altered if individuals are not knowledgeable of risk factors and risk reduction strategies.

The finding that the main source of cancer information for these participants was “others” may explain why these groups had such high levels of inaccurate cancer knowledge. As in this study’s findings, high levels of inaccurate and confused cancer knowledge as well as low levels of accurate cancer knowledge have been found in non-rural regions among low-income, low education level regions. This finding is similar to one from other studies in which low literacy and low income groups rely upon personal experience and “others,” not health professionals, for their information about health. The fact that these participants may not be seeking care or may not be receiving adequate cancer information from their health care providers, may explain why screening behaviors are low in rural Appalachia.

Cultural beliefs and attitudes have been found to be predictive of advanced cancer at diagnosis. Participants in this study used various anecdotes to explain their fatalistic attitudes about cancer. Despite treatment, the stories about cancer experiences shared within the groups almost always ended in death. The participants...
reported that fear and denial, or “not wanting to know,” were attitudinal reasons for not engaging in cancer screening and may likely be a contributing factor to the late stage cancer diagnosis found in this population. The concept of cancer survivorship, an inherent part of one phase of the Cancer Continuum, was rarely acknowledged by these participants.

The findings of this study are consistent with other studies that have found high levels of inaccurate and confused knowledge of cancer as well as lack of knowledge of cancer control among lower socioeconomic sectors.\textsuperscript{4,19,37}

Even though the counties in this study are economically disadvantaged, over half the participants were of an age to receive Medicare benefits. The concern expressed by all groups over lack of insurance and cost of cancer care may be a result of inaccurate knowledge or understanding of cancer care and the costs involved, and of the fact that treatment is covered by Medicare.

Analysis comparing the results of all nine focus groups has resulted in identification of several common themes (Table 5). Investigators pose these themes as areas for further study.

CONCLUSIONS

In summary, in all groups, knowledge levels about all of the cancers and about all stages on the cancer continua were low; and inaccurate knowledge was a predominant theme, particularly regarding risk factors and risk reduction strategies. Groups were more knowledgeable about symptoms, least knowledgeable about risk factors, and their responses often reflected uncertainty about the knowledge they had. The benefits of cancer screening and the early detection of cancer were not appreciated by these groups. These attitudes coupled with the multiple barriers to quality health care reported, are just a few reasons why rural Appalachians may not be participating in cancer control efforts and why cancer in this region is more often discovered in advanced stages. Attitudes, beliefs, and perceptions in these groups suggest the similarity between rural Appalachian communities and other underserved and disparity populations.

This study illuminates several areas of concern. Improving the content of cancer communication messages, increasing the use of and role of primary care providers in cancer communication, and removing financial barriers to health care are necessary actions if quality cancer control is to be achieved in rural Appalachia. Unless the perceptions, attitudes, and knowledge of the population can be altered, and improvements made in the presence of quality healthcare and its use, reduction in the already high cancer death rates is unlikely to take place. Further investigations to meet this challenge in this Appalachian population are clearly indicated.
Table 1. Comparison of County and National Cancer Statistics
(1994-1998, Age Adjusted Mortality Rates to 2000 standard population per 100,000, male and female combined)

<table>
<thead>
<tr>
<th>County</th>
<th>% Poverty</th>
<th>Lung</th>
<th>Colorectal</th>
<th>Breast</th>
<th>Prostate</th>
<th>All Cancers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boyd, KY</td>
<td>16.6</td>
<td>69.7</td>
<td>31.1</td>
<td>37.6</td>
<td>31.9</td>
<td>232.1</td>
</tr>
<tr>
<td>Cocke, TN</td>
<td>20.9</td>
<td>72.7</td>
<td>28.1</td>
<td>28.2</td>
<td>26.8</td>
<td>238.4</td>
</tr>
<tr>
<td>Campbell, TN</td>
<td>21.3</td>
<td>98.8</td>
<td>21.5</td>
<td>32.8</td>
<td>25.9</td>
<td>255.1</td>
</tr>
<tr>
<td>Harlan, KY</td>
<td>29.9</td>
<td>105.2</td>
<td>18.8</td>
<td>26.3</td>
<td>41.4</td>
<td>265.5</td>
</tr>
<tr>
<td>Lee, VA</td>
<td>28.5</td>
<td>84.7</td>
<td>25.4</td>
<td>22.8</td>
<td>26.1</td>
<td>225.5</td>
</tr>
<tr>
<td>Perry, KY</td>
<td>27.4</td>
<td>77.4</td>
<td>19.0</td>
<td>33.0</td>
<td>32.0</td>
<td>230.8</td>
</tr>
<tr>
<td>Smyth, VA</td>
<td>17.3</td>
<td>70.7</td>
<td>21.0</td>
<td>35.2</td>
<td>22.4</td>
<td>209.9</td>
</tr>
<tr>
<td>Sullivan, TN</td>
<td>13</td>
<td>68.8</td>
<td>23.4</td>
<td>25.2</td>
<td>43.1</td>
<td>217.7</td>
</tr>
<tr>
<td>Wise, VA</td>
<td>23.1</td>
<td>93.9</td>
<td>19.5</td>
<td>36.8</td>
<td>43.0</td>
<td>274.3</td>
</tr>
<tr>
<td>National</td>
<td>13.3</td>
<td>58.4</td>
<td>22.3</td>
<td>29.6</td>
<td>35.3</td>
<td>208.3</td>
</tr>
</tbody>
</table>

Table 2. Demographic Characteristics of Groups and Participants

Groups (n=9)*

<table>
<thead>
<tr>
<th>Type of Group (n=9)*</th>
<th>Gender/Ethnic Group Composition</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=9)</td>
<td></td>
</tr>
<tr>
<td>Church Groups (n=4)</td>
<td>44% Black Female Group (n=1)</td>
</tr>
<tr>
<td>Senior Group (n=1)</td>
<td>11% Black Male Group (n=1)</td>
</tr>
<tr>
<td>Women's Groups (n=3)</td>
<td>33% Hispanic Female (n=1)</td>
</tr>
<tr>
<td>Men's Groups (n=2)*</td>
<td>22% White Female (n=1)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11% White Male (n=1)</td>
</tr>
<tr>
<td></td>
<td>11% White Mixed Gender (4)</td>
</tr>
<tr>
<td>*(one men’s group included in church groups)</td>
<td></td>
</tr>
</tbody>
</table>

RURAL APPALACHIAN CANCER DEMONSTRATION PROJECT
### Total Participants (n= 79)

#### By Gender (n=79)
- Males (n=24) 30%
- Females (n=55) 70%

#### By Race (n=79)
- Black (n=15) 19%
- Hispanic (n= 7) 9%
- White (n= 57) 72%

#### Ages (n=78):
- 20-30 (n=7) 9%
- 30-40 (n=3) 4%
- 40-50 (n=5) 6%
- 50-60 (n=14) 18%
- 60-70 (n=17) 22%
- >70 (n=32) 41%

Table 3.

Cancer Care Continuum and Main Focus Group Questions

<table>
<thead>
<tr>
<th>Phase in Continuum</th>
<th>Sample Focus Group Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk Factors</td>
<td>What are the things that contribute to the development of _______cancer?</td>
</tr>
<tr>
<td>Risk Reduction/Screening</td>
<td>What can you do to decrease the chances of getting or dying from _______Cancer?</td>
</tr>
<tr>
<td>Symptoms</td>
<td>What are the symptoms of ______cancer?</td>
</tr>
<tr>
<td>Detection/ Diagnosis</td>
<td>What does the doctor do to detect/ diagnose _______cancer?</td>
</tr>
<tr>
<td>Staging/Treatment</td>
<td>How does the doctor diagnose? What are treatments of _______cancer?</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>How are symptoms/ treatment side effects cared for?</td>
</tr>
<tr>
<td>Resources (for cancer control)</td>
<td>What (healthcare/ cancer) resources are available in/ outside your community?</td>
</tr>
<tr>
<td>Clinical Trials</td>
<td>What are clinical trials? How do these benefit people? Do</td>
</tr>
</tbody>
</table>
you see a role for yourself?

<table>
<thead>
<tr>
<th>Survivorship</th>
<th>What are the needs of someone who survives ___cancer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>End of Life Care</td>
<td>What support services are available if someone has terminal________ cancer?</td>
</tr>
</tbody>
</table>

Table 4.

**Inaccurate Symptoms of Cancer Reported by Group Participants**

**Lung Cancer:**
- “chronic indigestion”
- “fluid on the lungs”
- “gray skin tones”
- “sweet body odor”
- “fever”
- “craving something sour”
- “jaundice”
- “no symptoms until it’s too late”

**Colorectal Cancer:**
- “No symptoms”
- “Constant pain”
- “swelling in ankles”
- “You just know when you have it”
- “hurt and swell”

**Prostate Cancer**
- “Swollen in wrong place”
- “blood in the stool”
- “enlarged”
- “soreness”

**Breast Cancer**
- “sore lump”
- “soreness in arm, can’t lift your arm”
- “discoloration”
- “breast swelling”

Table 5.-**Themes**
1. Inaccurate, confused and/or lack of knowledge about cancer
2. Negative perceptions of healthcare access & quality
3. Fatalistic perceptions of cancer and cancer treatment
4. Diet/ food as cancer risk factor and cancer risk reducer
5. “Others,” not health professionals, as main source of cancer information
6. Multiple barriers to cancer control services
7. Negative personal experiences with cancer
8. Prayer in response to cancer diagnosis, cancer treatment, survivorship, end of life care
9. Clinical trials believed to be experimental, risky, and without benefit
10. Work, home, and community environments perceived as cancer risks
11. Depression and denial as psychological aspects of cancer
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