

# Barriers to Cancer Screening by Rural Appalachian Primary Care Providers

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**ABSTRACT:** *Context:* Rural Appalachia has significantly higher overall cancer mortality compared with national rates, and lack of cancer screening is believed to be one of the contributing factors. Reducing the cancer disparity in this region must include strategies to address suboptimal cancer screening practices by rural Appalachian primary care providers (PCPs). **Purpose:** To identify and investigate barriers to recommending and/or performing cancer screening among rural Appalachian PCPs. **Methods:** A semistructured focus group research design was used to elicit perceived barriers to recommending and/or performing cancer screening from 36 rural Appalachian PCPs (in 5 groups), including physicians, nurse practitioners, and a physician assistant. **Findings:** Findings indicate that rural Appalachian PCPs may not be performing recommended cancer screenings for a number of reasons. Time constraints, conflicting guidelines, and perceptions that patients do not value prevention were reported barriers to cancer screening. The PCPs in this study expressed frustration in attempting to encourage cancer screening and cited patient factors such as socioeconomic status, Appalachian culture, and cancer fatalism as barriers to cancer screening. **Conclusions:** Rural Appalachian PCPs encounter various barriers, such as lack of time and multiple cancer screening guidelines, to incorporating cancer screening into their practice routine. The findings underscore the negative impact of some cultural factors on preventive care delivered by PCPs. Increased provider education is needed on how best to encourage cancer screening within a cultural context and should include clarification and understanding of current cancer screening guidelines.

The cancer burden in Appalachia is well documented as a geographic disparity, and lack of screening is believed to be one of the causes.<sup>1</sup> For example, women residing in the Appalachian region have significantly lower breast and cervical cancer screening rates when compared with other regions in the United States.<sup>2</sup> Compared to national cancer death rates (166.7 per 100,000 population) and the entire 13-state

Appalachian region (173.1/100,000), rural Appalachia has significantly higher overall cancer death rates (176.3/100,000), and areas in rural central Appalachia carry the heaviest cancer burden.<sup>3</sup> Death rates from cervical cancer are significantly higher in rural Appalachia (3.1/100,000), and colorectal cancer death rates (17.2/100,000) are higher in Appalachia when compared to national rates (2.7, 16.9 per 100,000, respectively).<sup>3</sup> Although cancer disparities are often associated with racial and ethnic minority groups, white males in predominantly rural central Appalachia have the highest lung cancer death rates in the country.<sup>4</sup>

Screening, and thus early detection, is possible in more than 50% of occurring cancers, and, except for primary prevention, it is the most effective strategy in reducing cancer morbidity and mortality.<sup>5</sup> The cost of inadequate cancer detection and screening is great. At present, 77% of individuals diagnosed with breast or colorectal cancer will survive at least 5 years after diagnosis, but this survival rate would increase to 95% if recommended cancer screenings were being performed on all Americans.<sup>5</sup> The economic costs of inadequate cancer screening are high. Colorectal screenings that cost on average \$125 can identify cancer before symptoms appear, after which the cost is approximately \$100,000 with a survival rate of only 8%.<sup>5</sup>

Studies have shown that physicians' cancer screening practices vary depending on patient characteristics.<sup>6,7</sup> The Institute of Medicine recently

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reported that disparities in health care are often provider-based and a consequence of physician time pressures, provider bias, language barriers, and geographic locations.<sup>8</sup> Traditionally, one element of the primary care provider's (PCP) role in cancer control has been to assure regular screening. PCPs are responsible for performing and/or recommending cancer screening, but this function often competes with the need to address acute problems and manage chronic illnesses.

Many studies have investigated cancer screening practices of PCPs by using survey instruments and chart reviews. Barriers to cancer screening reported by physicians include lack of training, confusion about cancer screening guidelines, lack of time, perceived patient disinterest, and uncertain efficacy of screening test.<sup>7,9</sup> These studies were in geographic regions other than rural Appalachia and did not include nurse practitioners (NPs). Even though NPs are increasingly providing primary care in rural communities, literature on cancer screening practices of NPs is scarce.

This is the first study to investigate barriers rural Appalachian PCPs encounter when attempting to incorporate cancer screening in their practice. Consequently, the investigators used a qualitative methodology (focus groups) best suited to initially identify key variables that could be used in future quantitative studies.

## **Methods**

Participants were identified from East Tennessee State University's (ETSU) College of Medicine and College of Nursing rural PCP databases. PCPs who practiced in 4 predominantly rural Tennessee counties (Hamblen, Johnson, Sullivan, and Washington) and attended patients from rural areas in Northeast Tennessee were recruited to participate in the study. Recruitment efforts included requests via mailed letters and telephone calls to attend a focus group meeting about their roles in cancer screening. Three of the 4 counties in which the participants practiced had been identified by the National Cancer Institute (NCI) as having higher cancer death rates when compared with national rates, as well as demonstrating a rising trend (1976–2000) in cancer death rates.<sup>1</sup> The focus group meetings were facilitated by the first author and conducted as described by Krueger and Morgan.<sup>10,11</sup> Only 5 focus groups were conducted, during the period January 2003 to June 2003, as the investigators reached saturation for new themes at this point. The focus groups ranged from 3 to 14 participants and lasted approximately 1 hour. Of the 71 PCPs invited by request letters, a total of 36 PCPs participated, thus yielding a 51% response rate. The semistructured format focused around questions designed to elicit from the PCPs their

perceived barriers to the following cancer screening procedures for 4 cancers: breast cancer (mammography, clinical breast exam); prostate cancer (PSA, digital rectal exam [DRE]); cervical cancer (Pap smear); colorectal cancer (fecal occult blood test, sigmoidoscopy/colonoscopy). The investigators chose these cancer screening tests as they are among the most commonly performed and/or recommended cancer screening procedures by PCPs. The main questions and prompts were based on current literature of barriers to cancer screening and included the topics (1) barriers to cancer screening, (2) knowledge of cancer screening guidelines, (3) impact of guidelines on practice, (4) patient characteristics that affect cancer screening, and (5) strategies to increase cancer screening in their practice and community. A research assistant was employed to assist with note-taking and transcribing. Meetings were audio taped and transcribed verbatim.

A brief demographic survey was completed by the participants that also included items asking the participants how often they recommended cancer screening and the type of cancer screening they were least likely to recommend and/or perform.

**Data Collection and Analysis.** Data collection and analysis occurred iteratively.<sup>12,13</sup> After each focus group, the authors independently reviewed the transcripts and notes to identify emergent central issues. Over several meetings, they compared and combined their independent analyses until consensus was reached. Emerging themes were expanded and explored in subsequent focus groups. The second step in the analysis involved determining the similarities, differences, and potential connections among key words, phrases, and concepts within and among each focus group transcript. Finally, the themes and subcategories of all focus groups were compared and contrasted, and the quotes that most accurately illustrated the themes were identified. Demographics and other survey items were grouped and quantified.

**Protection of Human Subjects.** The investigators have attended and successfully passed institutional review board (IRB) training on conducting research involving human subjects by ETSU. IRB approval was obtained from ETSU before implementation of the study. Informed consent was obtained immediately before each meeting from each participant with a cover letter explaining the study and requesting their participation.

## **Results**

Study participants included 27(75%) family physicians, 7(19%) nurse practitioners, a physician

assistant (3%), and a clinical nurse specialist (3%). Almost all of the participants (97%) practiced in a multiprovider practice of PCPs. Four of the 5 focus groups consisted of PCPs who practiced together in the same multiprovider group. Years of practice ranged from 5 or less years to more than 20 years, with more than half (53%) having practiced less than 5 years.

When asked how often they recommended cancer screening in their practice, only 13(39%) of the rural Appalachian PCPs reported recommending screening to all adult patients. Almost half (45%) of participants reported recommending cancer screening frequently, and approximately 15% of the participants reported recommending cancer screening sometimes or occasionally. Forty-five percent of participants reported the PSA was the screening procedure they recommended least often; 27% said sigmoidoscopy/ colonoscopy was least recommended, followed by 12% for digital rectal exam, 11% for fecal occult blood test, and 6% for Pap smear.

Differences in cancer screening practices and perceived barriers to cancer screening by type of provider were not evident in the survey data or focus group discussions.

Two major themes emerged from the analyses of the focus group discussions as determinants of cancer screening: (1) patient-focused barriers (fatalism, strong religious beliefs, present day-to-day orientation, and screening and health prevention not considered a priority); and (2) provider-focused barriers (lack of time and resources, conflicting guidelines, screening not part of the regular routine, and lack of provider continuity) (Table 1).

**Theme 1. Patient-Focused Barriers in Rural Appalachia.** Most participants reported that patients' fatalistic view of cancer, certain religious beliefs, low educational attainment, lack of knowledge about cancer, orientation to day-to-day living, and the Appalachian culture were barriers to recommending and/or performing cancer screening. Participants indicated that patients would frequently not comply with recommended screening or refuse it based on beliefs that cancer is inevitably fatal or because of pervasive religious beliefs advocating the predetermination of health and illness by a higher power. Examples of participants' statements include:

- “They say ‘I’ll have whatever I’m gonna have . . . .’ There is a fatalism that has something to do with the religious values in the community.”
- “They believe cancer is an automatic death sentence.”
- “They have a strong faith in Christ and He’ll take care of

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### Emerging Themes From Focus Groups with Primary Care Physicians and Midlevel Providers (N = 36)

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#### Patient-focused cancer screening barriers in rural Appalachia

- Fatalism
- Strong religious beliefs
- Low educational attainment
- Lack of cancer knowledge
- Present, day-to-day orientation
- Screening and health prevention not considered a priority

#### Provider-focused cancer screening barriers in rural Appalachia

- Lack of time
  - Screening not part of the regular routine
  - Lack of provider continuity
  - Conflicting guidelines
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them. And if He chooses that they have cancer then that’s the way it’s supposed to be anyway.”

“A patient may feel if ‘I’m gonna get it, I’m gonna get it anyway’ and just maybe don’t appreciate that cancer screenings and prevention might make a difference.”

Participants often reported that many of their rural Appalachian patients lived day-to-day vs planning for the future. They believed this sort of thinking worked against cancer screening behavior, which necessitates future thought and contributes to cancer fatalism. The lack of appreciation of preventive health care, and specifically cancer screening, increased the risk of cancer being discovered in late stages, and thus more likely terminal, reinforcing fatalistic thinking. The PCPs cited this present-oriented thinking, level of education of their patients, and lack of cancer knowledge as barriers to cancer screening evidenced by statements such as:

- “... patients’ level of education sometimes. They don’t see it [cancer screening] as an important necessity, so they just live life day by day. You know, ‘Whenever I get something and feel sick, I’m going to come in.’”
- “I don’t think people around here think long term . . . . I don’t think they think long term about diet and what they eat. I don’t think they think long term about health care.”
- “... low income folks. They tend to be more present-oriented. They also tend to be more fatalistic. ‘What will be, will be.’ There’s nothing I can do about it anyway.”

Many participants indicated their patients do not place a priority on screening and prevention:

- “... [they] really don’t think about preventive care very much at all. They wait till there’s a problem then they come in and have it checked.”

"Yeah, I have patients come in and say, 'Look, I'm only going to be seeing you when I'm really sick. I'm not coming in for regular checkups or annual exams. I have to be pretty sick or you'll never see me.'"

**Theme 2. Provider-Focused Barriers in Appalachia.**

Lack of time was one of the most common barriers reported by the participants, in particular, the high number of patients seen each day. Cancer screening was viewed as requiring extra time to counsel and teach. Also mentioned were the frequency of noncompliant patients ("no-shows") and most patient visits being for acute problems:

"Time constraints. I see 30-35 patients a day . . ."

"I often recommend a preventive visit and I schedule a visit, and they just don't come back."

"No shows for follow-up screening. They're really high."

"Let's face it; we only get some very valuable time with those patients. So if they don't come in or if I have to try to convince patients over and over, sometimes I just sort of say, I give them the one-time deal and if they don't come back, they don't get screened."

"Nobody's got the time to do health maintenance when people come in for acute visits. You just concentrate on their immediate problems and let them go on."

A number of providers explained they did little screening at their clinical setting because it was often not part of the regular routine at their rural clinic:

"A lot of the women get Paps at the local health department, and that doesn't mean they don't get wonderful adequate care, but that means it also is not part of their regular routine at a regular clinic."

"That's common [screening elsewhere] in rural areas in Appalachia."

An interesting finding was that provider continuity was viewed as a barrier to cancer screening. Several reasons were given: (1) many visits were for acute problems, and most patients never saw their regular primary provider on acute visits; (2) most of the providers in these rural settings only worked part-time in the clinics; and (3) many of the providers interviewed did not live in the communities they served. Participants reported statements such as:

"Continuity issue . . . patients that are seen acutely for work-ins . . . work in doctors . . . see them. So almost never do you see your primary doctor on an acute visit. We have a lot of patients who only come for acute visits . . . I've never in an acute visit looked at the chart . . . take the time to do counseling about cancer screenings."

" . . . only 1 out of 9 of the NPs in our clinic who lives in the community and practices there full-time. Maybe 3

work full-time and the rest of us are part time and live outside of the community and I think that can be a barrier to continuity of care."

Another provider-focused barrier was about conflicting cancer screening guidelines. Many complained that clinical practice guidelines for recommended cancer screening changed frequently, differed between agencies, and were often conflicting.

"Conflicting guidelines may make practitioners think, Well, I don't want to do this if they really don't know . . . ."

"If the experts can't make up their minds then I'm going to wait until the jury comes back in with a definitive answer before I go to the trouble of making these recommendations routinely."

"Whether to order a PSA . . . it's very confusing . . . ."

"Even colon cancer guidelines, some say over 50, some say over 40. Some call it sigmoidoscopy, some say colonoscopy . . . . And some say the rectal exam or the occult blood."

**Discussion**

Investigation into the causes of health disparity is a national priority and goal of Healthy People 2010.<sup>14</sup> Cancer incidence and death rates are a health disparity in rural Appalachia, and low screening rates by patients and providers are believed to be one of the primary causes. The study's participants were rural PCPs practicing in Northeast Tennessee, a region in central Appalachia with significantly higher cancer death rates when compared to national, Appalachian, and rural Appalachian rates.<sup>3</sup> The rural Appalachian PCPs in this study reported low cancer screening rates in their practices, supporting previous studies of low cancer screening by PCPs in other geographic regions.

The participants discussed multiple patient-focused barriers to cancer screening. Numerous behavioral, attitudinal, and geographic factors have been cited in the literature as barriers to cancer screening in rural populations.<sup>14</sup> In this study, providers cited the Appalachian patients' limited cancer knowledge, low education levels, fatalism, poverty, and rural residence as adversely affecting screening rates.

The rural Appalachian PCPs in this study viewed predominant cultural beliefs of their patients as a major barrier to cancer screening. Cultural factors are increasingly being recognized as contributors to cancer disparities.<sup>15</sup> Previous studies have found that non-Appalachian health care providers view Appalachian health behaviors negatively and tend to

stereotype patients from this region.<sup>16</sup> Predominant health beliefs of the Appalachian culture have been described by health care providers as fatalistic and characterized by passive acceptance of illness as God's will and reliance on religious faith.<sup>17</sup> Cultural beliefs and perceptions such as fatalism and underappreciation of preventive health care have frequently been identified as barriers to patient participation in cancer screening. In this study, the PCPs' perceptions of the cultural beliefs of their patients were identified as a barrier and underscores the influence of the "cultural gap" in the patient-provider relationship, which may have a more detrimental effect on preventive health care than previously thought.<sup>18-20</sup> The extent to which perceptions of patients' cultural beliefs impacted cancer screening behaviors by these providers was not discernable in this study. Interestingly, only 1 study has been conducted on reducing the effects of cancer fatalism on cancer screening.<sup>21</sup> Addressing patient-provider cultural differences for the improvement of health care may be considered too difficult a task.

Patients' low educational attainment and lack of cancer knowledge were also cancer screening barriers reported by the PCPs and are other examples of previously reported patient barriers to cancer screening. Knowledge of cancer risk factors and perceptions about cancer survival have directly been linked with patient cancer screening behavior; women with high knowledge levels of cancer risk and cancer survival are much more likely to engage in regular screening practices.<sup>22</sup> Moreover, lack of knowledge about cancer screening and its benefits have been found to adversely affect cancer screening practices of men.<sup>23</sup> Patient requests of cancer screening increase provider cancer screening behavior. However, patients must be somewhat knowledgeable about cancer if they are to request screening from their physician. The participants in this study indicated that their patients' lack of cancer screening knowledge, and thus patient expectation of screening, was a barrier to cancer screening.

The participants reported that their patients were day-to-day oriented and presented mostly for problem-focused visits. Notably, one reason cited by older patients for lack of cancer screening is the perception of the physician being problem-focused and not prevention-oriented.<sup>24</sup> The PCPs in this study reported patient disinterest in cancer screening as a reason for low cancer screening, but this runs counter to what is reported in the literature; patients' lack of screening behaviors are often reported as physician-centered. Patients are willing to participate in cancer screening if their physician recommends it, and lack of physician referral is a chief reason for not getting cancer screening.<sup>25-27</sup> In 1 study, the main reason

women did not get mammograms was lack of physician referral.<sup>28</sup> However, these studies were in areas other than the rural Appalachian region.

Contrary to what patients say, physicians report patient-centered reasons as barriers to screening for cancer. In a national Canadian study, family physicians were surveyed to determine the influence of various patient and physician factors in deciding to screen for cancer. Patient anxiety about cancer, patient expectations of cancer screening, and a positive family history of having cancer were the most significant factors in deciding to screen.<sup>7</sup>

To a lesser extent, practice-oriented issues such as time and provider continuity were perceived as barriers to cancer screening. These barriers are commonly reported in the literature as barriers to preventive health care services due to health care provider shortages common to underserved areas and not exclusive to rural Appalachia.

Conflicting guidelines were also a reported barrier to cancer screening and a source of frustration for these PCPs. The participants frequently indicated their uncertainty of what the most current cancer screening recommendations were at any given time. There are numerous cancer screening guidelines developed by several health and medical organizations, some of which vary significantly, change frequently, and conflict depending on the site, patient risk level, gender, age, and lifestyle behaviors (ie, being sexually active).<sup>29</sup> This study found that provider confusion over cancer screening guidelines translated into less cancer screening.

**Study Limitations.** Due to the sample size and methodology, generalization to the larger population is limited. Focus group methodology is limited by the type of information participants may disclose in a group setting. The data of this study are based on the perspective of health care providers and not patients. Different perspectives of patient and provider-focused barriers to cancer screening may possibly be obtained from patients themselves. The sample size was quite small; however, the authors believe that they obtained an appropriate sampling of the target population's opinion in that they attained saturation after 5 focus groups.

## **Conclusions**

The rural Appalachian PCPs in this study reported multiple barriers to recommending cancer screening to their patients. Most of these were patient-oriented barriers such as fatalism and lack of cancer knowledge but also included practice-focused barriers such as lack of time and conflicting guidelines. Perhaps the most

noteworthy finding of this study is how the Appalachian culture was perceived by these PCPs as a cancer screening barrier and underscores the negative impact of cultural differences on preventive care delivered by PCPs. Interventions aimed at access and education will have only limited success if cultural influence on health behavior is not addressed, in particular with regard to Appalachian-based providers. Furthermore, provider education should target understanding and clarification of current cancer screening guidelines.

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