

The Mountains Hold Things In: The Use of Community Research Review Workgroups to Explore Cancer Disparities in Southern Appalachia

Kelly A. Dorgan, PhD. and Sadie P. Hutson, PhD, RN, WHNP
East Tennessee State University

Department of Communication and Department of Family/Community Nursing

RURAL APPALACHIAN CANCER DEMONSTRATION PROJECT

ABSTRACT

The purpose of this project was to review research findings about cancer disparities from the RACDP (Rural Appalachian Cancer Demonstration Program) studies and identify grass-roots community leaders' perspectives about what makes the experience with cancer different in Appalachia. A community based participatory research approach guided this study both theoretically and methodologically. Twenty-two grass-roots community leaders formed two Cancer Research Review Workgroups in Tennessee and Virginia. The Workgroups engaged in a series of sequential sessions designed to present current research about cancer disparities in Appalachia and to investigate potential partnerships between communities and related healthcare providers and agencies to address these disparities. Although there is not one dominant variable which makes the cancer experience in Appalachia unique, this study yielded data which demonstrated a confluence of cultural, geographical, and environmental variables as contributors.

Three major themes were inductively derived from the workgroup transcripts, including (see Table 1):

- 1) cancer stories (e.g., stories about the cancer continuum);
- 2) cultural factors (e.g., healthcare system fatalism); and
- 3) healthcare access (e.g., economic access barriers).

Workgroup participants provided advice regarding addressing cancer disparities, cancer communication and cancer research in Appalachia. Specifically, participants advocated for patient navigator/advocate services, the use of cultural insiders to reach communities, and the importance of patient/provider communication. The findings from this study provide a unique foundation from which healthcare providers can begin to address cancer disparities in the Appalachian region.

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BACKGROUND

Stereotypes of Appalachia took hold by the late 1800s when journalists, missionaries and travel writers promulgated the image of the uneducated, impoverished "hillbilly" (Williams, 2002). Today, economic gains in Appalachia have created a diverse region that is largely still overshadowed by entrenched stereotypes:

Gains have transformed the Region from one of almost uniform poverty to one of contrasts: some communities have successfully diversified their economies; some are still adjusting to structural changes in declining sectors; and some severely distressed areas still require basic infrastructure, such as water and sewer systems (Appalachian Regional Commission, 2006).

Appalachia is a distinct region which stretches from New York to Mississippi, including Tennessee and Virginia. Researchers have demonstrated an excess of chronic disease and related mortality in the mountainous and rural areas of Appalachia. Many parts of the region have been federally designated as health professional shortage areas (HPSA) resulting in inadequate numbers of healthcare providers and inequitable healthcare services. In addition, economic distress, low educational attainment, and environmental characteristics have been linked to adverse health outcomes. The culmination of these factors is a likely cause of the poor health of Appalachians.

While economic improvements have benefited parts of Appalachia, excessive cancer-related mortality rates are still being documented in the region (Appalachian Regional Commission, 2004; Mulcahy, 2006), in part explaining the creation of initiatives such as the Appalachian Cancer Network to help address higher cancer-related mortality and morbidity (see Burket, Mulcahy, & Zahorik, 2006). While Appalachia's population is increasingly becoming urbanized (Stewart Burns, Scott, & Thompson, 2006), rural populations continue to face their own challenges. Rural populations have often been identified as being underserved in cancer screening (e.g., breast cancer screening; see Schootman, et al., 2000). In addition to social and economic barriers to screening, communication barriers also exist (e.g., lack of provider recommendation for screening; Allen et al., 1999). The purpose of this project was to review research findings about cancer disparities from the RACDP studies and identify grass-roots community leaders' perspectives about what makes the experience with cancer different in Appalachia

METHODS

The Rural Appalachian Cancer Demonstration Program (RACDP) was initially funded in 2001 to explore, identify, document and describe cancer disparities in the Central Appalachian region including East Tennessee, Eastern Kentucky and Southwest Virginia. During its first year, four broad exploratory objectives were established. Findings from these objectives led to identification of several key themes and these themes were explored in subsequent years. In total, the Program engaged in twenty

different research studies over a four year period. Each project encouraged the interaction of professional and community views in an iterative process to gain further depth of understanding why cancer outcomes seem poorer in the region.

The Program was initiated using a community-based participatory research approach through conducting structured focus groups and educational sessions in nine rural Appalachian communities (three in each state). In an effort to conclude the Program using the same approach, the Program organized two Community Cancer Research Review Work Groups, one in East Tennessee and a second in Southwest Virginia. The overall purpose of the Work Groups was to facilitate grassroots leaders review and comment on the RACDP projects findings. The objective was form Work Groups of twelve non-health professionals in each state.

Four educational sessions were conducted in each site using summaries of Program findings. Faculty facilitators engaged Work Groups in discussions of findings. A [fifth session](#) was organized separately or in pairs by each Work Group member; its purpose was to allow members to share salient findings within their communities and social networks. A sixth session, combined the two Work Groups with RACDP Program Investigators to discuss perspectives about “what makes the experience with cancer in Appalachia different and why?”

A community based participatory research approach guided this study both theoretically and methodologically. Twenty-two grass-roots community leaders formed two Cancer Research Review Workgroups in Tennessee and Virginia. The Workgroups engaged in a series of sequential sessions designed to:

- introduce the findings from RACDP;
- invite insight from a community perspective of these data;
- promote a dialogue between the Workgroup and health providers to identify methods for improved collaboration; and
- integrate the Workgroup with regional efforts of the state Cancer Control Plans.

Each focus group session was audio-recorded and transcribed verbatim; NVivo 2.0 facilitated qualitative content analysis of the narrative data. The goal of this type of analysis is the formation of themes from the observation of verbal and non-verbal data cues and the coding of those data (Neuendorf, 2002). Illustrative quotes used throughout this report are identified by a workgroup and session label only to preserve confidentiality of participants (e.g., a quote drawn from the Tennessee workgroup's third session is identified as, **TN-S3**).

RESULTS

Research Question 1: What makes the cancer experience unique in southeast Appalachia?

Participants' reflections about cancer disparities yielded new insights regarding the experience of cancer in Appalachia. Although there is not one dominant variable which makes the cancer experience in Appalachia unique, this study yielded data which demonstrated a confluence of cultural, geographical, and environmental variables as contributors. Three major themes were inductively derived from the workgroup transcripts including: 1) cancer stories; 2) cultural factors; and 3) healthcare access. It is important to note that the three major themes are not mutually exclusive categories, but rather should be viewed in aggregate. The major themes and sub-themes are presented below, but can also be referred to in Table I.

CANCER STORIES

Some scholars argue that "the combination of geographical isolation and tight family and community ties fostered a culture of storytelling" in parts of Appalachia (e.g., Olson, 1998, p. 73). This oral tradition appears to also encompass issues surrounding health and illness. The cancer experience in Appalachia may be unique, in part, because of the storytelling tradition. These ***cancer stories*** appear to be "trapped" within mountainous, rural communities, bouncing within and between families and influencing perceptions about health, healthcare, and cancer in Appalachia.

Cancer Everywhere

One emergent theme surrounding cancer stories involved the ubiquitous nature of cancer in Appalachia. One participant in Tennessee stated, "They [community members] expect to get [cancer]. They all do. It's almost like it's inevitable" (TN-S1).

Participants shared stories—both personal and from community sources—during the workgroup meetings. They shared stories about how former classmates had died prematurely of cancer (VA-S1), as well as how people at work and at church were diagnosed:

Well, back in the 70's there were in my church probably about a ½ dozen women that had a mastectomy; and this in a church with fewer than 80 members [...] You know, it was fairly generally known to other women that this had been their experience and there were also teenage girls who became aware of this and they got very anxious for fear that they would develop breast cancer (VA-S2).

In addition to widespread stories of cancer in the community, there also emerged evidence that stories were passed to younger generations (e.g. teenage girls). By transferring stories from one generation to the next, fear and anxiety also appeared to be transferred; thus, stories continued to affect cancer screening behaviors.

Cancer Continuum

Stories cited by participants stretched across the cancer continuum. For example, one story linked fear of doctors to refusal of *cancer screening*, a refusal that can be passed down through generations:

I know that people have a great fear of doctors and sometimes do not go because of that - because someone has told them a story. I have a 62-year-old sister who has never had a female exam. Not breast or anything else. That's because my mother after she had her last child, she didn't go to the doctors for 40 years after that. And, so that fear was transferred to my sister (VA-S2).

Another participant discussed fear of the screening exam as a barrier to cancer prevention efforts:

If you just hear about what is involved with some of these test you think, "Oh that's horrible, I don't want to do that." And people are afraid. They are truly afraid and so they put it off when it is not as bad as they think it is going to be (TN-S1).

The majority of cancer stories were negative in tone, usually underscoring the challenges of navigating the cancer experience. For example, various community participants' personal stories described the challenge of being shuffled around in the healthcare system while trying to get family members diagnosed. Others shared stories they heard in the community:

I just heard a cancer patient say, "They (healthcare providers) sent me home for two days and I was so bewildered and so terrified and I couldn't even ask anybody anything" (VA-S2).

Moreover, negative **treatment stories** can affect both families and the larger community. "You know you hear stories," one participant said, "like my father-in-law had a tumor [...] at the base of the spine and brain and he would go to Duke and they would do radiation and it would shrink. And, then he kept getting worse." Unfortunately, after the father-in-law had surgery, he had the "mind of about a three-year-old child" (VA-S1). This underscores the idea that cancer treatment potentially impairs quality of life, thereby suggesting to community and family members that the treatment is worse than the disease.

Stories appeared to "percolate" in the community, influencing generations of attitudes about and behaviors toward cancer and cancer care. One predominant story that emerged focused on **causes of cancer** in Appalachia. These stories seem to linger in communities, at times helping people make sense of cancer in their region. In particular, the stories signaled an ongoing debate between the factors of hereditary and

environment. Many participants thought "cancer was like more a hereditary thing" (VA-S1) because of the devastating family history of the disease. Heritage was consistently mentioned in cancer stories. Whether it was family heritage or community heritage (e.g., coal mining as a causal agent), workgroup participants offered narratives rooted in confusion and anger which suggested a love-hate relationship with industries which were a part of their mountain heritage.

I mean you know, when that coal is discovered it is bound to release some kind of toxin. Because I can't remember cancer being as prevalent before the stripping (strip mining) began as it is now (VA-S3).

Participants questioned whether certain Appalachian families were at the mercy of their genetic make-up or environmental factors, such as environmental pollution or radon. Communities shared stories about illegal waste dumping that affected water sources and pollution that was trapped by the mountains.

And if you remember several years ago, there was a big story about illegal dumping up there (TN County). [...]how many of these hollers are repositories for lots of chemicals? I know a place I used to work for, it was rumored that they buried a lot of the radioactive waste underneath the slabs on site (TN-S1).

Participants from both Virginia and Tennessee suggested that the pollution from local industries was held in by the mountainous terrain. This also appeared to be happening with culturally-bound stories and values. Simply put, due to the unique make-up of the mountainous parts of the Appalachian region, communities are affected by all the ingredients (e.g., stories, environment, values) in this "geographical stew."

I've always heard about all this because we are in the mountains, you know? [...] The stuff that makes them smoky and holds everything down and you know I heard particularly older people say that too...that the mountains kind of hold things in, you know? That we breathe more. The air quality...

CULTURAL FACTORS

Because of the historic isolation of some Appalachian communities and families (Olson, 1998), arguably generations of Appalachians have come to rely on their social networks for physical and psychological health. Since doctors were rare to this area--a chronic shortage that remains today (Baldwin, 1999)--community members were sometimes left to practice self-care. Moreover, suspicion of "outsiders" (e.g., "invasion" of missionaries from the North; stealing of mineral rights; for review see Olson, 1998; Williams, 2002) may have been passed down through the generations, possibly resulting in families and communities tightening their loyalties to *ingroup members* (e.g., families, churches; Gudykunst, 2003) and becoming more suspicious of *outgroup members* (e.g., strangers such as "foreign doctors"). As a result, it is possible that

when it comes to matters of health, family and community members' opinions matter as much, if not more than, doctors' opinions.

Cancer Collectivism

Familism has long been documented as a dominant value in Appalachia (see Williams, 2002). The family structure may impact the entire cancer continuum, especially given that "in few places does the family remain as essential a component of culture and society as in Appalachia" (Stewart Burns et al., 2006). Because of geographical and economic barriers, rural families and communities have to rely on themselves. In turn, this can create the need to be loyal to the collective and thereby subordinate one's personal needs to the needs of the family. A recent publication describes psychological collectivism as a construct consisting of five aspects: 1) preference for in-groups; 2) reliance on in-groups; 3) concern for in-groups; 4) acceptance of in-group norms; 5) and prioritization of in-group goals (Jackson et al., 2006). These facets resemble important elements of the experience of cancer in Appalachia. For example, the diagnosis of cancer, especially when it is asymptomatic, may not occupy a high priority in a person's life since it would require an expenditure of resources (e.g., money, time) that may be better spent on family's immediate and pressing needs, thus suggesting a deep concern for ingroups and prioritization of ingroup goals above personal goals.

Most of this whether it's lack of information, lack of treatment... the inability to even think beyond. They are surviving day-to-day. They don't have time to think about whether they're going to survive five years from now. So they put [going to the doctor] off. That's just one more trouble they don't need to work with. They need to feed the baby tomorrow (TN-S1).

Illness Self-Reliance: Saving Face and Preserving Privacy. Since illness can place a heavy burden on small, interwoven communities and families, **illness self-reliance** may be a particularly important tool for saving face and for protecting the community and family.

Well, I see most of the people in this area as being very private and they don't necessarily want "so and so" down the road to know about their health problems. They tend to keep it more "in house" so to speak (VA-S2).

(My father) don't even talk to my mother (about his colon cancer). I mean, we don't want to burden anybody else with our financial problems, our health problems, our family problems (TN-S1).

One important aspect of illness self-reliance that emerged from the data was that of **self-treatment**. Many participants related stories about uninsured community members who needed to depend on home remedies to treat their cancer symptoms,

especially since the cost of diagnosis and treatment would place a financial burden on ingroups.

We had a discussion with some of the housing community people and a lot of them lost theirs (TennCare), said they are going back to old remedies and praying a lot because they don't have the money for health care (TN-S1).

My uncle died of cancer and he found out because they went with old remedies. You know, there wasn't money then to do a lot of things. So his finger got cut off and he went to the emergency room and went back to get the stitches out because they sewed the finger back on and it wasn't healing right. They did tests and he had cancer (TN-S1).

Traditional Gender Roles. In familism, strict gender roles have been documented (see Williams, 2002) where families emphasize the father as provider and mother as caregiver (Stewart Burns et al., 2006). In Appalachia, while roles are shifting, traditional gender roles may still impact the cancer experience and communication about cancer.

Yeah, it is kind of hard for a guy to say "I got this knot on me." Whereas you know women, you know, they can [...] bond better than us macho bald headed guys (VA-S2).

While community participants generally agreed that there was a need for privacy about health matters within Appalachian communities (e.g., to preserve one's status; to avoid burdening others), this need for privacy may be particularly acute among Appalachian males. As one participant said, "I just think men are more private in this area" (VA-S2). Likewise, another participant suggested the notion of **saving face** when saying:

They tend to see it more as a stigma in most cases- men do. Whereas women don't see it in a negative concept, they look to other women for support. Men tend to be more closed-mouth when it involves something like cancer (VA-S2).

There was some evidence that men would talk with other men about cancer as long as they had some shared experiences, perhaps underscoring the importance of **leveling** in Appalachia (e.g., having the same status; see Williams, 2002). One participant shared how her husband, recently diagnosed with cancer, would talk with other male survivors in his lawnmower shop.

He runs a lawnmower shop and he doesn't talk a lot to me. I don't know if he thinks it will worry me, but he comes home and says I talked with so and so and they had so and so done and they done fine. I mean, he has talked to two or three dozen people through his work. So he does talk to people about it and he

tells people what is wrong, which surprises me [...] But he is generally doing that man to man. His shop is full of men (VA-S2).

In summary, a person's sense of **place** in the community appears to profoundly affect the Appalachian cancer experience. Family and community members have to be concerned about upholding traditional gender roles, preserving limited resources, and generally not burdening their tightly woven communities.

Healthcare Expectations

Rural health disparities have long existed in the United States; however, such disparities in Appalachia have been particularly problematic. Geographical isolation and economic conditions (e.g., company-owned towns providing the only available healthcare) have combined to create unique healthcare challenges in mountainous, rural Appalachia (Mulcahy, 2006). Generations of Appalachians have faced these challenges, helping to shape present-day expectations about cancer and healthcare.

Healthcare System Fatalism. Throughout the community workgroups, there appeared to be a sense of pessimism regarding **their place in the healthcare universe**. That is, some participants said that Appalachians are regarded as "second-class citizens," (VA-S1) especially when it comes to healthcare. It is important to note that this healthcare system fatalism is different from the more general fatalistic approach to healthcare which has been described in the literature regarding Appalachian individuals.

In Appalachia, we are [...] last to get anything, medical tests, MRIs, the good doctors (VA-S1).

First, there are still substantial portions of rural Appalachia that are uninsured or underinsured (see Mulcahy, 2006); therefore, it is understandable that people may be fatalistic about their ability to even **access** the healthcare system (to be discussed in more detail below). One story about "a lady that had a bad Pap smear" exemplifies this issue:

She lived on Highknob with a mate, a male that stayed drunk all the time. [...] she had to go to the Health Department because she had no money and no insurance and she had two or three Paps and they all came back bad and they couldn't even get a hold of her. [...] they had no phone, no computer. There is people like that here [...] there are people that even if they could get help they feel like they're hopeless and she was like that. She could go to the Health Department, but she just, you know, I guess their circumstances were so dire. I mean they were sleeping in sleeping bags (VA-S2).

Second, there is the challenge of **navigating** the system once a patient has accessed it. As one participant said about his personal experiences with the local

healthcare system: "the most frustrating thing for me [...] is the right hand not knowing what the left hand is doing. (VA-S1). Several community participants shared negative stories about trying to obtain services and information (including test results) from healthcare professionals.

(We) had an appointment. We go back over and we are told that the doctor left at 11 o'clock that morning by the time we got to his office. So that was 48 hours (after the initial lab work). On the following Thursday, we called and we talked to the nurse practitioner. The nurse practitioner said, "You know, I realize your sense of urgency. You know I can lose my job for this because of HIPPA laws. I don't know why the doctor has not contacted you." She said, "I'm going to tell you because I know you need to know what you need to know." She is the one who told us that there was no mention of cancer in the lab report. You know, why did the doctor not called us? He ought to have common courtesy to at least have called us (VA-S2).

Another participant shared a story about community members trying to navigate the "big hospitals" and the confusion surrounding the absence of a healthcare advocate.

here they go into the big hospital and they are shuffled around, given papers, I've seen it happen, you know. You go do this, you go do that. There's not really an advocate, somebody that is going to take the time and explain to them. And a lot of times you have a physician or resident who doesn't speak very good English...But it's like they're being shuffled through the system (TN-S2).

The availability of physicians was often traced back to the healthcare system and the fact that doctors had to schedule so many patients to run "through a mill for fees" (VA-S2). This may be especially prevalent characteristic for physicians practicing in Appalachia where poverty and lack of insurance are common barriers to healthcare.

My own doctor didn't have time to talk to me. And, I said "Listen, if I taught your child and I taught school [location omitted] for 35 years [...] I taught your child and wouldn't talk to you, how you would react? If I didn't have time for you." [...] No more than 5 to 7 minutes they're (doctors) allotted (VA-S2)

Patient-Provider Trust Predicament. Successful healthcare interactions involve trust, especially in securing patient-compliance; however, shared stories about contradictory information and fear of the provider can erode trust at the community level. For example, one participant said, "You hear a lot of talk in this area about, 'Well, I went to that doctor and the doctor did me no good,' or 'That doctor let my momma die.' There is a lot of distrust" (VA-S2). This distrust may be heightened by the perceived lack of a personal connection between Appalachian patients and their providers.

I don't think doctors are that involved with their patients anymore. I can't tell you how many times in the past two or three years that I've noticed. [...]How many

times have you gone in and you've had to refresh their memory of why you're here. If they ever read your chart. They have no idea. "Okay, what are we here for today? What did we do last time?" You know, 3 minutes of your 7-1/2 minutes is wasted bringing them up to speed (TN-S1).

Perhaps further aggravating Appalachian patient-provider relationships are regional norms involving ingrouping/outgrouping and privacy that may interfere with **patient assertiveness**. That is, patients may be confused, afraid, and distrusting, but because of entrenched cultural norms, they may not address their concerns **with their doctors**. While some community participants thought that Appalachian patients were becoming "a little bit more aggressive" (VA-S2) in part due to increased levels of education, there still seemed to be a fear of questioning doctors.

They have a fear of sitting down one-on-one with the doctor. Asking the doctor questions because most doctors belittle you and they won't answer your questions so you will understand them (VA-S2).

This fear of questioning healthcare providers appears to affect whether Appalachian patients seek **second opinions**. While several participants indicated that they would seek second opinions, one participant said about her experience with cancer: "You all make me feel bad. I should have gotten a second opinion" (VA-S2). There was an expressed concern that seeking second opinions may be "damaging the relationships" with their doctors:

A lot of people won't do it because they're afraid they'll make their doctor angry (VA-S2).

Due to the geographical and historical challenges outlined above (e.g., poor access to independent healthcare), some rural Appalachians may not yet recognize basic patient rights.

A lot of people don't realize the standard of care that the doctor and health care provider is obligated to provide. [...] take charge of your own health, it's rarely done around here. So, I don't think our community knows the standard of care that our providers should give us. So therefore, we cannot say, "Did you check this?" (VA-S2).

Ultimately, then, Appalachian healthcare expectations may affect whether patients even bother accessing the system, as well as their behaviors once they are navigating the system. Patients who are distrustful and fearful of their physicians cannot fully participate in addressing cancer prevention and cancer care.

Cancer Expectations

While **cancer fatalism** in Appalachia has received considerable attention (e.g., Shell & Tudiver, 2004), recently, something akin to **cancer optimism** seems to be emerging in rural Appalachia. During this project, several participants indicated that there was still an “old school” sub-culture in Appalachia that believed that cancer was always fatal or that it could be spread by operating on a malignant tumor. However, there also was evidence of “faith” in screening and treatment opportunities and an unwillingness to give up on family members who have been diagnosed. One woman explained her husband’s beliefs, a man who she pointed out was 17 years her senior, and therefore, had different cancer expectations:

He (her husband) said [...] “Well, I’ve got to die of something.” [...] But he is following up. I won’t let him not (VA-S2).

Preferred Cancer Uncertainty. Rather than cancer fatalism, what was documented was an understanding that Appalachian communities may simply prefer to live with their uncertainty about cancer.

I know people. A lady I work with probably has tumors. Maybe cervical cancer and her doctor’s appointment last Friday got cancelled. And, she came back and went, “Well I’m glad.” And, I said, “What are you talking about? You’re glad you know that your appointment was cancelled?” And she was actually afraid of what they were going to find. And I think a lot of people are thinking, “If I ignore it, it will go away.” (VA-S2)

I also know at the beauty shop, you know how you listen to people talk, and the lady up there was talking about somebody who was having breast cancer and having a mastectomy and she said, “You know I haven’t had a mammogram or anything because I just wouldn’t want to know because I would rather die than be disfigured like that. My life would be over anyway” (TN-S1).

As a consequence of this preference for uncertainty, there appeared to be **cancer avoidance**. While there may be some access-related barriers underlying the avoidance (to be discussed later), there can also be a feeling that people living in Appalachia “don’t want to have to deal with” cancer (VA-S1).

Rather than facing and saying, “the sooner something is found the sooner something can be done,” a lot of it is fear [...] So they tend not to go (TN-S1).

Cancer avoidance may be in part due to the “hectic and hurried” lives of Appalachians (VA-S2). Screening when asymptomatic may be low on the priority list, especially when a person is coping with the challenges of extended family and other acute health problems. **Life priorities**, then, may serve as barriers to screening, actually helping people avoid the topic of cancer.

One thing is the trouble to getting to [screening], 'cause they are always held during working hours, and so if they are working, they got to be on the job. They can't take that time off. And some of it is just immediate needs. They don't perceive it as an immediate need unless there is a history of it, some sort of, something happens "well I have got to go in and get checked." [...] We can't even get them there to take their kids for check ups to get them into school. It's hard enough to get them to do that, let alone get them in for themselves, when they're not sick (TN-S2).

In summary, the community workgroups revealed that while **cancer optimism** may be becoming more evident than **cancer fatalism** in rural Appalachia, there is still a resistance to assertively pursuing cancer screening. Essentially, **Life** appears to get in the way, forcing some Appalachians to choose cancer uncertainty over preventative healthcare.

[In]Credible Agents

Appalachia has a unique set of ingroups and outgroups. Ironically, while healthcare providers, especially those from Appalachia, carry a great deal of authority, there are other ingroups that carry as much—if not more—authority regarding health matters.

Church. The church emerged as a central source of information about cancer, making it a **credible agent** of health information and healthcare advice. As one Tennessee participant said, "That's what I have heard a lot in [my] county. If you want to get something done, you have to go through the churches (TN-S3). Similarly, a Virginia participant explained that most "conversations about cancer" she listened to took place in her "church group" (VA-S2). There was an implied trust between church members, making them influential sources, at times even more influential than healthcare providers.

We listen to those that are closest to us whether it is at church or whether it is in your immediate family. Like "You've had a bad experience and I'm not going to do that." (VA-S2).

What enhanced healthcare professional's credibility within the community was when those providers were part of the existing religious ingroup. Repeatedly mentioned was the "parish nurse," someone who was a bridge between the Appalachian community and healthcare community.

we had a couple of health professionals who were members of the church. One of them was a nurse. The good thing is that we had a women's meeting that included teenage daughters and the nurse showed them how to do the breast exams and talked to them about signs of breast cancer to relieve their anxiety.

They shared experiences and information. I found that very healing and helpful (VA-S2).

Family and Personal Networks. Another credible agent generally cited was the family/personal network. It is this "influence of family" that has often been noted as a feature that distinguishes Appalachia from much of the United States (Stewart Burns et al., 2006). As with the church, trusted ingroup members sometimes served the role of bridge between the healthcare community and Appalachian communities. One participant previously trained but not practicing as a nurse, said, "Well, everybody in my family uses me as their advocate because I know something about the medical field."(VA-S2).

Participants expressed the need to trust and be comfortable with their cancer communication partners.

This gentleman, when we went to see him yesterday who has cancer, he said, "Well, you didn't tell anybody what's wrong with me, did you?" We said, "No, we just told them that you are having some tests." He said, 'Well, that is fine.' So there is a stigma about telling someone that you have cancer (TN-S3).

Family, friends, and even co-workers were often stated as being more credible to participants than doctors. Personal networks can provide a "pat on the back" and reassurance that "everything is going to be okay" (VA-S2). Comparatively, workgroup members said "a lot of people can't face what the doctor may tell them" (VA-S2), further indicating that many in Appalachia prefer uncertainty and cancer avoidance over cancer certainty. In fact, during one Virginia workgroup session, the majority of participants stated that they **would talk** to family and friends about cancer, but they **would not** talk to their doctors (VA-S2).

Healthcare Providers. Navigating the system requires that both healthcare providers and patients be comfortable and skilled with cross-cultural communication. Both parties come from different cultures (e.g., the doctor coming from the organizational/hospital culture) with unique languages, norms, beliefs, and values. For example, to address the rural physician shortage, some programs are providing incentives for foreign-born medical residents to practice in medically underserved areas of Appalachia (Baldwin, 1999). Yet, to have a successful doctor-patient interaction, both parties must be aware of their differences (e.g., beliefs about treatment) and competent in overcoming those differences (e.g., ability to ask and answer questions).

Those living in Appalachia may have particularly complex relationships with their doctors. Ironically, Appalachian patients simultaneously see physicians as knowledgeable but **not** necessarily as credible agents of health information and healthcare advice, at times rendering healthcare providers, especially physicians, as **"incredible" agents**:

People don't trust them enough to go and have a mammogram and do all the things...a lot of them don't go to doctors (VA-S2).

Several participants acknowledged that there are "mixed feelings" in Appalachia about doctors (VA-S2). However, what appears to make healthcare providers "trustworthy" is when they are **both** a medical professional and an Appalachian. Perhaps, this is why the "parish nurse" was repeatedly mentioned as a trusted partner in cancer communication (VA-S2; VA-S6). Likewise, another participant offered the following:

The most successful doctors offices here are those where the doctor from this area has gone off to medical school and then comes home to take care of their community. Those are the best doctors. (TN-S3).

State Government. Both Virginia and Tennessee workgroup members consistently indicated that their State Governments lacked credibility in rural Appalachia. This lack of credibility (i.e., "**incredible**" **agents**) was largely due to perceptions that Appalachia is largely ignored by government leaders.

We are in the armpit of Virginia. Everybody sort of perceives Virginia stops in Roanoke (VA-S4).

Similarly, in Tennessee, one participant stated that the Tennessee Cancer Control Plan may be particularly helpful because, "We will finally get some recognition that there is some state passed Knoxville. I mean seriously, you hear it all of the time; it is like you get to Tennessee and to Knoxville and that is where the state stops" (TN-S4).

Participants seemed to tie **Appalachian invisibility** into existing stereotypes. Perhaps because of the distasteful image of rural, mountainous Appalachia that currently prevails (Williams, 2002), state governments may overlook this region:

We've had such bad press from some of the things that have happened here over the years. People come in here from Washington or places and they don't see the good things about the area. They mostly pick out the poverty and language and the fact that we are coal mining and how bad it looks in places [...]that's all that people see about our area (VA-S4).

There was considerable anger voiced about the state governments overlooking Appalachia. As one participant said, they "don't even know that we even exist" (VA-S4). Another offered: "The person in the holler is going to say, 'What, Richmond doesn't care about us'" (VA-S4).

I think the legislative body and our government and state has sort of forgotten about us because of the population is spread out throughout a large area here

[...] I think that has caused a lot of the problem with education and with the communication about the cancer (VA-S4).

Appalachia's invisibility, according to many workgroup members, was reflected in ongoing cancer research and outreach efforts. For example, participants at times wondered why local physicians and cancer advocates at the state level did not make appearances at local health fairs.

Well, they don't have any reason to come this way. You know and the State doesn't have conferences on this end of the State. If they have a conference, they have it in Roanoke or Virginia Tech (VA-S4).

there really isn't a way that people in our community would really know about them (Tennessee Comprehensive Cancer Coalition). I mean I didn't see any ads on TV or anything written or any news flashes or big articles in the newspapers. So there is no way for people other than word of mouth to know about them and you would think that they would have at least sent these (brochures); since it is a state thing, to the state health departments (TN-S4).

While there was little to no knowledge of state cancer control plans, some optimism was voiced about possible partnerships between community and State. In particular, participants thought "regular people" (VA-S4) from Appalachia needed to be involved in the creation of state cancer control plans. Participants from the Tennessee workgroup were also optimistic about the benefits of the State Cancer Control Plan:

...if you think about all the people you know in your family there is hardly anyone that isn't touched by cancer. And to know the state was alive and well and doing something positive would be good (TN-S4).

HEALTHCARE ACCESS

Issues regarding access to healthcare system and healthcare information emerged on several levels including physical access, economic access, and cancer information access.

Physical Access: Geography and Transportation

Geography and transportation issues are commonly cited as barriers to obtaining medical care (Mulcahy, 2006). Unlike other mountain ranges in the United States, the Appalachian mountains consist of only four distinct geological provinces. Despite this, the rugged physical geography has "shaped life and culture in the region from the arrival of humankind" (Byerly and Renton, 2006 p. 3). Byerly and Renton (2006) also note that early settlers to the region established themselves in places which were most fertile, but that those who settled where survival was problematic started what has become an "enduring social hierarchy" (p. 5). Participants repeatedly discussed lack of

transportation or difficulty reaching healthcare facilities due to rough terrain as well as difficulty accessing community members who lived in the “hollers.”

I think transportation is an issue too [...] because you’ve got people up in the hollars (TN-S1).

Some of it is transportation. [...] Even though we have (public transportation), it may cost .50 cents. And, I guess I’m thinking about this one lady and they did bring her over to [the university] and talked to her about a lot of things, but I think her income was like a 100 and some dollars a month and she had custody of the grandchildren so it really was their check. And she said by the time she paid the rent and got the other necessary things, it was nothing left...transportation is a problem for her (TN-S1).

Economic Access

As previously discussed, issues of healthcare system fatalism and preferred cancer uncertainty are likely linked to access-related barriers. Participants repeatedly told stories and expressed concerns regarding economic access to healthcare in Appalachia. In addition to the aforementioned stories regarding a lack of cancer screening follow-up due to limited financial resources, participants described an avoidance of free clinics related to pride.

Some of the people that are up in the hollers are very proud and they don’t want to go to free clinics. They are like, "If I can’t pay for it myself, I’m not going to do it" (TN-S1).

Insurance. The lack of health insurance seemed to be a primary concern. Some thought the high cancer rate throughout southeastern Appalachia was in part "because people don't have health insurance," rendering them unable to go to the doctor (VA-S1).

I thought about that with a friend of mine, I use to be friends; she’s no longer with us. But because she didn’t have healthcare [insurance] she kept putting off going to the doctor ‘cause she didn’t have the money. She had gotten laid off from her job, she had two children, so her main concern was how to feed those kids, not take care of herself. After about a year it had gotten so bad she went to the emergency room and then the doctors there referred her to on, and that time she got the help. But the day they diagnosed her one year later then she died, exactly to the day. [...] So I think a lot of people [...] may have jobs, but the jobs don’t offer [insurance] (TN-S2).

Cancer Information Access

Upon addressing the question, “What makes cancer different in Appalachia?” another theme that emerged was that of cancer information access. Whether it was

understanding information about cancer or being able to **physically access** information, participants expressed concern. For example, participants pointed out that doctors and cancer researchers have often failed to tailor their messages to the Appalachian population:

Well, I think that many people in this area; even if they have access to the information, they can't understand it [...] it's that language barrier. Where are they going to find that information? There is not a computer in everyone's household hooked to the Internet [...] That's a big barrier for this area (VA-S3).

Participants underscored that cancer healthcare providers and researchers use "big words" and sound like they are "talking down" to the population they are attempting to help (VA-S3). One participant added, "We have quite a few people who still do not read" (VA-S3).

To help address cancer information needs, workgroup participants emphasized the use of **community resources**, such as churches and health fairs as important and valued sources of cancer information. Again, the emphasis was placed on the need for local healthcare professionals to: 1) be visible by participating in community-driven organizations and events; and 2) make sure cancer communication is tailored to the unique cultural and linguistic traits of their Appalachian patients.

Lack of Information. There was a concern about ability to access information in Appalachia. For example, while new media (e.g., the Internet) were seen to provide important opportunities for disseminating information, there was a suspicion that without assistance (e.g., from healthcare providers and librarians), many in Appalachia would not be able to take advantage of those sources.

My stereotype image is that people in California and those other places are going to immediately be more savvy with Internet and other kinds of information they can search out information, whereas here in a rural area, a lot of people don't even think to do that. And they just feel immediately more overwhelmed and more helpless, probably more hopeless than the ordinary person would who is already going to be more overwhelmed and that is going to be with everybody (VA-S2).

Overall, participants were concerned about Appalachia being left out of ongoing cancer research and cancer communication efforts. They were "shocked" at the high cancer rates in Appalachia, even those who were cancer survivors (VA-S1) and worried that the region was unaware of "technology" (VA-S2) that could help in the fight against cancer. Others linked their own lack of information to what was happening throughout Appalachia.

I had no idea of what testicular cancer was. I had never heard of it and that was at age thirty. With degrees and everything, I had never heard of it. [...] this is

where I was thinking about listening to this discussion, the dissemination of information in the Appalachian region. How are these people getting their information? Look at the circulation rates of the newspapers-they are not very big. Outside of that you have got television, and I guarantee you that most people are not tuned to most of the stations that give them this kind of information. [...] the ignorance is appalling [...] So I am wondering where do they get their information; apparently from nowhere (TN-S1).

In summary, data from the research review workgroups are congruent with existing concerns about access-related barriers in Appalachia. Yet, beyond economic and physical access issues, access to cancer information emerged as a barrier to cancer care.

DISCUSSION: COMMUNITY-BASED ADVICE

Research Question 2: Are community-based groups helpful to cancer communication?

Upon answering the question posed above, the investigators asked workgroup participants to share any advice they had related to improving cancer care in the community and partnering with the academic community to help bridge the cancer disparities gap. The importance of appreciating the participants' stories became exceedingly apparent through the avenue of advice. This technique has been used to increase experiential depth in prior studies (Hutson & Alter, 2006). Workgroup participants provided insightful advice regarding cancer disparities, cancer communication and cancer research. Specifically, participants advocated for patient navigator/advocate services, the use of cultural insiders to reach communities, and the importance of patient/provider communication.

Patient Navigator/Advocate

The concept of the patient navigator or lay health advisor has become increasingly important in recent years in the United States. In an area where there is a shortage of health professionals and a lower level of educational attainment, it is reasonable to assume that patient navigators could fill the gap between community members and health care providers; this was one of the most common recommendations among both Virginia and Tennessee workgroup participants. This is congruent with an existing literature that identifies community health advisor programs as a proven method of raising the health of individuals in Southern communities (Hinton, Downey & Lisovicz, et al., 2004). Participants explicitly discussed being lost without a health care advocate as well as needing someone to help "translate" medical terminology they found confusing.

Using Cultural Insiders to Reach Communities

Workgroup participants also discussed the importance of using cultural insiders, specifically community leaders, (e.g. church ministers, leaders of social organizations, parish nurses, etc.) to gain the trust of individuals when approaching them for health care services or research interests. One workgroup member stated:

If a stranger just appears as a stranger with a briefcase of whatever, I mean, I'm going to be suspect of that person [...] If I don't know who they are. You know, I'm going to be thinking, "Well, first off, who are you? What are you doing here? Why are you asking me these things?" (VA-S3).

This reinforces the idea that in order to effectively communicate and partner with disparate populations credible in-group members must be involved. Workgroup

members also advised that researchers and health care professionals become involved at local events. These ideas are heavily tied to the cultural factors identified above.

Enhancing Patient-Provider Communication

Advice surrounding patient-provider communication was abundant. Workgroup members specifically suggested tailoring cancer information to the individual patient. This notion is nothing new in health care. Thus, this message from workgroup members reinforces the very importance of communication as one of the most influential factors in improving patient-provider rapport. On a related note, workgroup members suggested that healthcare providers give patients follow-up information subsequent to the diagnosis of cancer or any other serious condition. Participants implied that their communities had difficulty identifying trustworthy sources of cancer information; healthcare providers, especially when working in cooperation with Appalachian in-groups, can be trusted sources; they were looked upon as necessary conduits of recommended resources.

Conclusion

In summary, the rich descriptions gained from twenty-two grass-roots community leaders in Northeast Tennessee and Southwest Virginia with diverse backgrounds, personalities, and life experiences yielded three major factors which make the experience of cancer in Appalachia unique: 1) cancer stories; 2) cultural factors; and 3) healthcare access. Moreover, the use of community participants has a distinct advantage: these leaders can return to their families and communities and serve as highly influential sources of cancer information and support. For example, some community-based activities that have taken place following these workgroups include:

- letter writing campaign to regional cancer center to urge use of patient advocates;
- formal and information presentations of cancer disparities research to co-workers, church members, family members and regional nursing students;
- membership and participation in the Tennessee Comprehensive Cancer Coalition and other regional cancer-related organizations; and
- newspaper articles discussing participation in the Cancer Research Review Workgroup.

The findings from this study provide a unique foundation from which healthcare providers can begin to address cancer disparities in the Appalachian region. Advice gained from participants will influence future research, education, and clinical practice as these findings are disseminated across the academic community. As cancer stories continue to percolate within these Appalachian communities, they will shape and reshape individual cancer experiences. The use of community based participatory research has added yet another level which may ultimately positively influence these cancer stories and healthcare attitudes and behaviors.

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Table I. Major Themes and Sub-themes Describing the Experience of Cancer in Southern Appalachia

| Cancer Stories | Cultural Factors | Healthcare Access |
|-----------------------|------------------------------|---------------------------|
| Cancer Everywhere | Cancer Collectivism | Physical Access |
| Cancer Continuum | Healthcare Expectations | Economic Access |
| | Cancer Expectations | Cancer Information Access |
| | Preferred Cancer Uncertainty | |
| | (In)Credible Agents | |