Special Challenges and Issues in Appalachian Communities

2009 Collaborative NCCCP and NPCR Conference
April 16, 2009
Atlanta, Georgia

“From plan to implementation to partnerships”
Program Overview

• Interagency Agreement between Appalachian Regional Commission (ARC) and CDC Division of Cancer Control

• Proposal funded to ETSU in September 2006, extended into 2009
  • Bruce Behringer, MPH, Rural and Community Health and Community Partnerships
  • Toni Bounds, PhD, MPH, College of Public Health
  • Jill Bumpus, BA, College of Nursing, Appalachian Center for Translational Research in Disparities
  • Other faculty from Nursing, Communication and Internal Medicine

• Create Advisory Board from Appalachian states, CDC and ARC
Program Goal

Demonstrate strategies that strengthen facilitators and weaken barriers to engagement of State Comprehensive Cancer Control Coalitions and Appalachian communities that result in short-term involvement and encourage long-term collaboration.
Purposes of Program

- Recognize differences in rural Appalachian population and its cancer issues
- Identify facilitators and barriers to local implementation of comprehensive cancer control coalitions and state cancer plans
- Model strategies to address challenges of Appalachian region to promote local cancer control implementation
East Tennessee State University
Activities in Appalachia

• Comprehensive Cancer Control Plans Implementation in Appalachian Communities Program grant was competitively awarded by ARC
• ETSU has been historically engaged in Appalachian health through multiple funding sources
• ETSU has conducted Community Partnerships programs since 1992 to educate health professional students in and with rural and minority communities
• Track record of community-based participatory research in cancer, diabetes, obesity and substance abuse
• Operates an NIH Appalachian Center for Translational Research in Disparities
Where is Appalachia?

- In 1965 Appalachian Regional Commission established
- Region contains 420 mountainous counties in 13 states (All WV)
- Uniquely positioned to partner with CDC on regional health issues
- ARC identifies economically distressed counties – also have poorer health outcomes
Common Facts About Appalachian Health

- Appalachia is seen as a distinct region with 23 million people.
- Region is mostly rural with few large cities (Pittsburgh, Knoxville, Winston-Salem, Birmingham).
- Appalachia has historic shortages of health professionals and health services.
- Many counties suffer from persistent economic distress and poor educational achievement.
- Mountain counties’ health statistics look more alike across state lines than across their own states.
Burden of Cancer in the Appalachian Region

- Appalachian mortality higher than national rates in 23 of 26 comparisons
- Clear issue with premature mortality (age 35-64)
- Particular problems with lung, skin, cervical and colorectal cancer
- Mortality patterns vary geographically within region by type of cancer
- In comparison with US all cancer mortality, Appalachian rates have increased by 10% and distress Appalachian county rates by 23% from 1969-2001
### Comparison of Cancer Mortality Rates by Age

**For Appalachian County Rates within Thirteen States With United States Rates, 1999-2004**

<table>
<thead>
<tr>
<th>Age at mortality</th>
<th>States</th>
<th>Percent of National Rate for All Cancers</th>
<th>Number of six cancers for which Appalachian rate is higher than state</th>
<th>Cancers for which rate exceeds 25% of national rate</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td>35-64</td>
<td>65+</td>
<td>35-64</td>
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<td>35-64</td>
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<td>65+</td>
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<tr>
<td>States</td>
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<tr>
<td>Alabama</td>
<td>115%</td>
<td>103%</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Georgia</td>
<td>105%</td>
<td>99%</td>
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<td>3</td>
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<tr>
<td>Kentucky</td>
<td>141%</td>
<td>116%</td>
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<td>6</td>
</tr>
<tr>
<td>Maryland</td>
<td>109%</td>
<td>101%</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Mississippi</td>
<td>119%</td>
<td>99%</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>New York</td>
<td>102%</td>
<td>104%</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>North Carolina</td>
<td>106%</td>
<td>97%</td>
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<td>4</td>
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<tr>
<td>Ohio</td>
<td>122%</td>
<td>108%</td>
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<tr>
<td>Pennsylvania</td>
<td>104%</td>
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<tr>
<td>South Carolina</td>
<td>109%</td>
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<tr>
<td>Tennessee</td>
<td>119%</td>
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<tr>
<td>Virginia</td>
<td>114%</td>
<td>102%</td>
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<tr>
<td>West Virginia</td>
<td>119%</td>
<td>110%</td>
<td></td>
<td>5</td>
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</tbody>
</table>

**Table Note:**
- The percent of the national rate for all cancers is shown for both age groups (35-64 and 65+).
- The number of cancers for which the Appalachian rate is higher than the state rate is also provided for both age groups.
- For cancers exceeding 25% of the national rate, both the 35-64 and 65+ age groups are listed.
Regional Signposts

- Asked Community Cancer Research Review Work Groups to identify their own community characteristics
- …but beware of over-generalizing and cultural stereotyping
- Use as signposts to guide way into and with community, not as fixed traits
- Appalachia is diverse
  - Geographically
  - Economically
  - Race, with special issues of small numbers

What we know about Appalachia:
Community members contribute views

- **Geographic characteristics**
  - Much of the population lives in small and isolated mountain communities
  - Strong personal and cultural identity with “place”

- **Health system and economic characteristics**
  - Rurality affects availability, mountains affect access
  - Mistrust: fear “being taken advantage of” by system
  - Lower incomes and poorer health insurance
  - Too few providers demonstrate cultural competence

From: Behringer, et.al. (2007). Understanding the Challenges of Reducing Cancer in Appalachia: Addressing a Place-Based Health Disparity Population, California Journal of Health Promotion
Cultural Factors – Sense of Self

• Appalachians identify themselves as a distinct, neglected or invisible region
• Personal sense of place – “Mountains Hold Things In”
  • Social networks support safety, physical and psychological health
  • Familism and traditional gender roles
  • Suspicion of outsiders and loyalty to “in-groups”
  • Illness self-reliance and self-treatment

• Health care system
  • Fatalism – based upon history of poor access, low navigation skills and cancer outcomes
  • Communication - Lack of patient assertiveness, not questioning providers and health literacy issues
  • Cancer avoidance and dealing with other life priorities
• Rely on credible agents with cross-cultural communication abilities
  • Churches, family networks and health providers
  • Being “one of us”
  • Not being government
Many cancer control efforts are local, unrecognized and not linked.

- Appalachian region’s characteristics: neighbors helping neighbors, in low key and informal ways
- Community leaders are involved in cancer activities but unaware of state cancer control coalitions or plans

Types of activities
- Fundraising, sponsoring events and benefits to help families, friends and neighbors
- Organize community for screening and educational programs
- Support through prayer calls and donations
- Local coalition development with local, regional or state affiliation
Putting an Appalachian Model into Action

- 2007 Appalachian Regional Cancer Forum
- Advisory Board recommended Request for Proposal process to promote models of engagement in 2008-9
  - Frame as partnerships
  - Link to state cancer plan goals
  - Identify community and state cancer control coalition expectations and benefits through Give-Get Grid
  - Use multiple models: storytelling projects, forums, roundtables
Capturing and Telling Your Community’s Cancer Story

RFP to rural communities tapping Appalachian cultural trait of Storytelling to engage people in cancer education and awareness
Wetzel County Cancer Coalition, WV

- Story circles at local church, helped by Extension Office
- Additional stories to be collected at Relays for Life
- Developed PowerPoint with audio to share across region
Blue Ridge Healthcare Cancer Center, NC

Story circles at cancer center
Created “Voice of Light” DVD
Survivorship stories
Turning into a live performance
Perform at NC survivors’ conference, support groups and educational outreach
Webster County Cancer Education Project, WV

- Sponsored by First United Methodist Church
- Story circles in home with survivors, families and caregivers
- Develop play, “Hope’s Café”
- Where rural people gather to talk about cancer journey across tables
- Performed at Mountains of Hope annual state coalition conference
Storytelling Projects

- Technical and artistic advice from Mountain Empire Older Citizens and Roadside Theater
- Found story circle approach very usable to “get people talking” and gather community stories
- Engaged performers with audience
  - Experiential, cathartic, and educational
  - Believable message senders
Replicating the Appalachian Cancer Control Forum

Regional meetings following the successful 2007 model
Responses to Forums RFPs

- Forums (6)
  - Kentucky - 2 (9/08, 5/09)
  - Ohio (11/08)
  - Alabama (11/08)
  - Virginia (4/09)
  - North Carolina (4/09)

Each proposal funded at $5,000
Forums Sample Agenda

Meetings conducted in Appalachian region

Sample agenda topics

- Welcome by local official or cancer leader
- State comprehensive cancer control coalition presentation (with state cancer plans)
- Regional cancer data by registry personnel
- “Best practices” from within region
- Defining mutual benefits (Give-Get Model)
- Planning for local action
Conducting Regional Roundtable Discussions to Understand Cancer Differences between Regions

Smaller meetings to gain community views of their cancer data
Response to Roundtables RFP

- Kentucky (10-11/08)
  - 6 development districts
- New York (11/08, 3/09)
  - 2 sub-regions
- Mississippi (9-10/08)
  - 2 consecutive meetings
- NC-VA-TN (1-2/09)
  - 6 urban and rural counties
- Tennessee (11/08)
- South Carolina (5/09)

- Each proposal funded at $2,500
Roundtable Sample Agenda

- Welcome of state cancer representatives and local participants
- Sharing of regional and state cancer data
- Information about Coalition and Plan
- Discussion about regional barriers, best practices, and/or solutions
Whose idea were these events?

- State rural health association
- Regional Komen Affiliate
- American Cancer Society affiliate
- Regional cancer control coalition
- Local college/university
- District health department and new regional foundation
- Area agency on aging
- Hospital system
- Local hospice facility
- State comprehensive cancer control coalition was required as applicant or supporter; most helped organize planning committees
Different models emerged for organizing events

- Meetings to identify regional issues then plan cancer control action (MS, NY)
- Regional forum identified issues then district roundtables helped to plan implementation (KY)
- Single cancer issue focus (AL)
- High cancer mortality county focus (TN)
- Part of existing structure of engagement
  - Komen bi-annual assessment (VA-NC-TN)
  - Issue for regional hospital network (NC)
  - Identify new model cancer control programs (OH)
Participants

- 460 attendees at 20 events
- From 350 participant evaluation forms:
  - 22% indicated membership in state coalition
  - 85% represented a state or local organization interested in cancer
  - 35% worked with Appalachian communities on cancer issue
  - 85% live in Appalachian region
Identifying Appalachian cancer attitudes and beliefs

Pre-event survey used semantic differential scales based on previous qualitative research findings to understand common regional beliefs

Sample scale

- First reflection of regional cancer beliefs
- More participants believe cancer is seen as fatal than curable
- One of 14 Scales
- Conference calls with sponsors helped to interpret event-specific and regional results
What event attendees identified as Appalachians cancer attitudes and beliefs

- Cancer is a problem in the region
- Cancer brings families together
- People in the region are economically disadvantaged
- People lack access to care
- Cancer is seen as fatal
- God determines cancer outcomes
There is variation within region on all beliefs

- **Mississippi roundtable**
  - Lesser belief that God determines cancer outcomes, maybe due to environmental nature of roundtable discussion

- **Central vs. North and South Appalachia**
  - Central Appalachians believe people tell stories about cancer
  - New Yorkers and Alabamians differed in believing people are silent about cancer
Finding Appalachian Regional Best Practices

- Event sponsors collaborated to identify “what works” in region
- All along the cancer care continuum
  - Patient navigator programs
  - Outreach support groups
  - Local groups to network cancer resources
  - Organize free screenings
- Reaching out to “my people”
Sources of Data Presented

- State Cancer Registry
- State Cancer Plan
- BRFSS
- Census
- Birth Surveillance System
- State Vital Records/Departments of Health
- American Cancer Society
- Appalachian Regional Commission
- Centers for Disease Control & Prevention
Types of data presented

- Incidence and Mortality
- Population Details
- Demographic-Specific
- Behavioral (Smoking, etc)
- Preventative Use (Mammography)
- Type of Cancer
- Data Comparison – County, State, National
Sample Forum Presentation of Data

- Created index with multiple elements: Mortality, Incidence, Behavioral (ie. mammography) and Risk (ie. high school achievement)
  - All Cancer
  - Lung Cancer
  - Breast Cancer
  - Colorectal
- Compared and ranked Appalachian vs. non-Appalachian Development Districts and found Appalachian Districts had higher burden of cancer
Sample Roundtable Presentation of Data

- Analyzed Cancer Registry Data for Mortality, Incidence, and Stage
- Compared Rural and Urban Counties, and Appalachian and Non-Appalachian Health Districts
- Types of Cancer:
  - All Cancer
  - Lung Cancer
  - Colorectal Cancer
- Identified significant variation by health district within the Appalachian region
Lessons Learned about Data

- Most registries had not analyzed the data this way before
- States used their own data
- Regardless of source, community and local professionals questioned any data
- Regardless of findings, participants were surprised by data
Role of State Partners

- State comprehensive cancer control programs and coalitions
  - Describe coalition structure and activities
  - Describe/disseminate state cancer plan
- State cancer registries
  - Analyze registry data for Appalachian counties
  - Present challenging data in meaningful formats that promote community interpretation
- Multiple purposes
  - Introductory and organizational
  - Shared event with old and new partners
  - Part of broader engagement agenda
  - Promote regional support for statewide agenda
State Program Reactions to Events

“a way of getting people together and open doors to new partners”

“we recruited new coalition members”

“helped to support the regional coalition and make the state coalition more visible”

“finding best practices meant us learning from our coalition members”

“we got community input about how to conduct a new state initiative in a region that had not been involved”

“this will inform our next cancer plan”
Summary:
What was validated by events

- Appalachia has special cancer problems defined by community and data
- This is only partially recognized by stakeholders
- There is a lot of cancer control activity in Appalachia conducted by communities and not connected to state plans or coalitions
- States in Appalachia want to expand activities in Appalachian regions
- Forums and roundtables promote local implementation relevant across the continuum
Lessons learned about RFPs as an intervention model

- Distributing small grant funds is difficult but much appreciated at local level
- Going there makes a difference
- Acknowledging community context, community resources and local beliefs makes a difference in planning interventions
Dilemmas Discovered

- Intuition about higher cancer rates but unaware of facts; susceptibility not translated into empowerment
- Cancer is a personal problem but elicits culturally supportive community response
- People will do more to help others than prioritizing time/resources to help self
- May need to rely on those who have already given the most (survivors) to be effective messengers
- State plan improvements occur and are supported at local level – and are human resource intensive
The Program Logic Model

Resources → Program Activities → Outputs → Outcomes → Impact

Mini-grants development
Increase initiation and interaction
Identify regional beliefs
Improve mutual awareness
Methods to engage community
Give-Get Grid

Process evaluation
Outcome evaluation

Recognize more cancer control in Appalachia
Dissemination: what we have learned


- Dorgan KA, Hutson SP, Gerding G, Duvall KL. Culturally tailored cancer communication, education, and research: the highways and back roads of Appalachia. *Preventing Chronic Disease*. April, 2009.
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