ABSTRACT

The Rural Appalachian Cancer Demonstration Program (RACDP) was supported to explore, identify, document and describe cancer disparities in the three-state Appalachian regions of Kentucky, Tennessee and Virginia. To accomplish this charge, researchers were engaged from multiple institutions. Both quantitative and qualitative approaches were used. This overview summarizes how the overall program design and many of the individual studies followed the principles of community-based participatory research (CBPR). Each of the nine CBPR principles is summarized and examples cited from RACDP studies.
INTRODUCTION

Cancer Disparities in Appalachia

The National Institute of Health (NIH) defines health disparities as “differences in the incidence, prevalence, mortality and burden of disease and other adverse health conditions existing among specific population groups in the US” (http://crchd.nci.nih.gov/chd/disparities_defined.html). The recognition of disparities in cancer outcomes or cancer-related health began in 1973 when Henschke published a paper documenting a significant increase in cancer related mortality in African Americans during the previous 25 years (1). This publication prompted the National Cancer Institute to raise awareness of racial differences in incidence and mortality from cancer. Since the publication of this report, there have been numerous reports outlining and emphasizing the prevalent gaps in cancer outcomes for various populations in the United States (1974)(2-6).

Cancer-related health issues and health care disparities in the United States have been associated with multiple factors. Racial and ethnic minorities, the poor and the elderly bear a disproportionate burden of cancer mortality. Biases, stereotyping, clinical communications and decision-making contribute to disparities in cancer care (7). Ward et al. outline the disparities in cancer incidence, mortality and survival and the relationship of these disparities to race, ethnicity and socioeconomic status. Data from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute indicates that when poverty is combined with particular racial groups, the data indicate the lowest survival rates are among cancer patients from poorer counties. Central Appalachia historically suffers from many of the same factors that negatively influence healthcare access and outcomes in other disparity populations. Its counties, particularly those in Central Appalachia, are characterized by lower income, greater lack of insurance coverage, and lesser availability of health professionals. High rates of risk factors and mortality have been documented (8). Rates of cancer mortality for the total Appalachian region have been reported, and recent findings identify higher rates for selected types of cancers in gender segments (9-12). More recently, a study supported by the Appalachian Regional Commission identified premature regional health disparities from multiple causes of mortality (13). Difficulty in access to cancer treatment services has been documented and services are not uniformly distributed. Public awareness, provider attitudes and current infrastructure for clinical trials is not optimal.

Given Appalachia’s largely rural nature, with its unique social and communication patterns, communities experience cancer in a personal way. There is general lack of understanding and public skepticism about state reported cancer rates and risk factors. Health professionals in the Appalachian area feel their region bears a disproportionate cancer burden. Professionals also question the accuracy of state health statistics. Inaccurate or non-specific causes of death on death certificates and travel across state
lines for medical care are among the issues casting doubt on the credibility of cancer data reports. Given these beliefs and experiences among communities and health professionals, it seems important to further explore and understand the true extent of cancer disparities in the region. There are specific challenges encountered in exploring geographic cancer health disparities in Central Appalachia. Measurements of cancer disparities are incomplete due to inadequate epidemiological data. Cancer registries in two of the three states in the study remain uncertified. Sub-state, particularly rural county analyses of risk behaviors and care seeking patterns are limited by small sample sizes collected in data sets such as the Behavioral Risk Factor Survey. Patients using cancer care services demonstrate considerable interstate care-seeking patterns because regional availability of cancer prevention and care services is uneven, resulting in the need for complex and legally challenging data sharing agreements between states.

**Background of the Rural Appalachian Cancer Demonstration Program**

East Tennessee State University (ETSU) received a Congressional appropriation in 2002 through the Centers for Disease Control and Prevention intended to identify, explore, describe, and document regional Central Appalachian cancer disparities. A regional collaboration was formed to include the ETSU Division of Health Sciences, the LENOWISCO Health District of the Virginia Department of Health, and the Markey Cancer Center at the University of Kentucky (UK). The program was entitled the Rural Appalachian Cancer Demonstration Program (RACDP).

The program model for RACDP’s exploration of into Appalachian disparities was based upon the belief that progress in addressing the cancer disparities required a substantial commitment to engaging communities with their health professionals in assessing cancer issues. To capture the richness of a culturally distinct region, the separate and interactive beliefs of community and health professionals were reviewed. The research plan blended qualitative and quantitative approaches that provided different insights and recommendations that substantiate the need for greater depth to health disparities research. The following is a description of the approaches used in pursuing four Program objectives.

Rural Appalachian Cancer Demonstration Program tested an alternative regional geographic disparities model. The research plan blended qualitative and quantitative approaches to identify differing insights about cancer and cancer care. These insights led investigators to explore initial findings that raised additional questions that required greater depth of inquiry to understand disparities issues. The work demonstrates the approach of engaging communities with health professionals in assessing cancer issues. The program model studied the influence of both medical resources (access, availability and use of services) and psychosocial and behavioural factors as instrumental to health outcomes.
Community-Based Participatory Research

Community-Based Participatory Research (CBPR) is a methodology being increasingly used in public health research. It has been widely used to help explain complex public health issues and their impact on different populations (Butterfoss, Goodman and Wandersman, 1993; Green and Mercer, 2001; Israel, Schultz, Parker, and Becker, 1998; Israel, Eng, Schultz, and Parker, 2005). This method has gained widening popularity in exploring public health problems specifically in minority populations to better understand not only how the culture of populations, but how those determinants affect health.

Using CBPR has been successfully used to explore differences in health and healthcare in multiple populations. CBPR approaches were employed to study disparities in a Latino community in California (Kim, Flaskerud, Koniak-Griffin, and Dixon, 2005). The CBPR approach yielded many benefits, such as facilitating lasting relationships between the community, the researchers and government agencies, resulting in culturally relevant findings and access to resources for future research and programming (Kim et. al., 2005). Studies with South African populations used CBPR to formulate relevant research questions regarding HIV-AIDS and cervical cancer that resulted in major changes to the intended study (Mosavel, Simon, Stade, and Buchbinder, 2005). Authors indicate that this successful community involvement will improve future interventions (Mosavel et. al., 2005). There are recent reports that CBPR has also been used to explore health disparities in Appalachia as well (Coughlin, Costanza, Fernandez, Glanz, Lee, Smith, Stroud, Tessaro, Westfall, Weissfeld, and Blumenthal, 2006; Huttlinger, Schaller-Ayers, Lawson, 2004; Denham, Meyer, Toborg, and Mann, 2004).

Because of the previous success of CBPR in Appalachian communities, it was decided that using it for many projects would be beneficial to the Program. Using this approach first identified the apparent statistical disparities, defined appropriate approaches, shared these strategies with community and providers, elicited research questions, and finally, identified strategies to seek further data about questions as a subsequent phase of the RACDP. The inquiry was formative, relying upon commentary gained from both patients and providers.

Using the Principles of CBPR to Identify, Document and Describe Cancer in a Three State Region of Appalachia

Israel and colleagues (Israel, 2003) describe nine principles of Community Based Participatory Research. CBPR principles framed the overarching philosophy of the approach of RACDP in exploring cancer disparities in the region. The method was also adopted by many of the individual research studies to guide community engagement. Examples can be found in an early study (#7) which used community-based focus groups in the three states to help identify community perspectives about cancer and cancer care issues. The final Study, #19, formed regional community work groups to review the summative overall findings of RACDP and identify unique rural Appalachian
issues. Examples from RACDP studies are described to explain how CBPR principles were adopted through individual studies are cited below. Studies are referenced using its report number in the CDC Final Report.

**Principle 1: Acknowledging the Community as a Unit of Identity**

Many RACDP projects addressed the issue of community cohesiveness. Study #19 recruited thirty community leaders from Northeast Tennessee and Southwest Virginia into Community Cancer Research Review Work Groups. The groups were asked to consider all RACDP findings, register their perspectives about finding validity for their regional community. Work group members clearly identified themselves with their Appalachian communities and reviewed findings based upon their community’s experience with cancer. Their community of identity was one of “place”, their mountains which influenced their beliefs and behaviors. Study #5 informally surveyed healthcare providers in health care practices in Kentucky, Tennessee, and Virginia to determine opinions about the utility and practicality of developing a patient-accessed electronic medical record system for cancer care. The electronic records were intended to facilitate communication among multiple cancer care providers and to allow patients to monitor their care and care options using nationally-agree upon guidelines. The record concept recognized patients’ perception that all cancer care providers and resources represented a singular unit. Similarly, responding providers viewed themselves as part of the health system that was the patients’ unit of identify.

**Principle 2: Building on the Strengths and Resources of the Community**

Many studies sought to identify community strengths as potential assets in research question design, in understanding how communities positively or negatively influence cancer risk, prevention, screening, diagnosis and treatment, and in design of cancer control interventions. For example primary care practices in rural communities are seen both as providers through which urban specialty care is secured and advocates for patients once referred. In Study #10, rural physicians and nurse practitioners served in focus groups to describe their perceived roles in the cancer care continuum among women patients with a diagnosis of cancer form their practice. The strong sense of affinity of providers and patients reinforced to the research team the importance of rural clinicians as resources in every step on the cancer care continuum. Another example, from Study #17, tapped rural African-American churches to identify the community’s experience with cancer. The study identified how churches are resources within their communities that can identify and translate culturally relevant issues about cancer.

**Principle 3: Facilitating a Collaborative, Equal Partnership in all Phases of Research**

Residents of Central Appalachia often feel powerless in dealing with institutions and research as well as distrust for researchers. Fostering a collaborative and equal process is beneficial to all parties involved and is important to the success of the study. This was demonstrated through the design of the Cancer Communication Workshop
(Study #8). Community members including cancer survivors and advocates shared perspectives about community beliefs about cancer and cancer care with clinicians and health organizations. In another example, Study #11 sponsored a series of focus groups with community leaders, business leaders, and healthcare providers to construct tailored educational messages for different populations in Central Appalachia. The outcome yielded positive results and the members of the community involved were satisfied and felt as though their opinion about cancer findings was used in communicating disparities issues.

**Principle 4: Fostering Co-learning and Capacity Building Among all Partners**

In Study #2 an interactive mapping WEB site was created early in the program to allow researchers and then the public to investigate cancer mortality rates for the three state area. The WEB site was used in community presentations with encouragement to participants to upgrade their own knowledge and skills to assess their county’s or state’s cancer issues. Of greatest importance was the WEB site’s capacity to be used to demonstrate differences, by geography (county), by gender, by race and by type of cancer. The use of the Cancer care Continuum to frame discussions in Study #7 with community groups helped community members understand their selected type of cancer while helping researchers learn about community knowledge and beliefs. The use of qualitative and quantitative findings was demonstrated in Study #17 with the African American community. The ability to present race-specific data to describe the “double disparity” of being black and Appalachian was instrumental to help the community to identify its key concerns. Those concerns in turn helped researchers to understand the community experience with cancer, the new learning sought by the study.

**Principle 5: Integrates and Achieves Balance Between Knowledge Generation and Intervention**

The development of the compact disk in Study #15 represents an excellent example of balancing the collection and use of new community knowledge about breast cancer. The investigators used information collected form several studies to formulate messages for primary health care providers that, when used, could improve communication with women about breast cancer screening. The PowerPoint presentations posted as Study #20 also demonstrate how findings from the Program were used in public and policy education to promote understanding and action about cancer disparities in Appalachia.

**Principle 6: Focusing on Local Relevance of Public Health Issues**

The RACDP grant was a product of rural community intuition that there is more cancer in the Appalachia than other parts of the country. Cancer always appears in lists of health issues generated by communities. Study # 2 mapped cancer morality rates by county (and gender and race) for all types of cancer. These maps were presented to
audiences of community and regional leaders (Study #18) to reconfirm cancer as an acknowledged public health issue. The intense interest and relevance of environmental factors in cancer continued throughout the Program, first being investigated in Study #3, and raised in the community focus groups (Study #7), the cervical cancer high and low county comparison study (#12) and continued even through the Study #19 Community Research Review Work Groups.

Principle 7: Involving Systems Development Using a Cyclical and Repetitive Process

The overall design of the RADCP Program was based upon a cyclical approach to exploring cancer issues. As a beginning and end of the Program, its initial Study (#7) used community-based focus groups in the three states to help identify community perspectives about cancer and cancer care issues. The final Study, #19, employed regional community work groups to review the summative overall findings of RACDP and identify unique rural Appalachian issues. The repetitive process is exemplified through the example of cancer communication. Findings from the community focus groups (Study #7) were used to formulate questions for Study #8, the Cancer Communication Workshop. The outcomes of the Workshop promoted additional qualitative inquiry about cancer screening issues and refined and tested factors that influence provider recommendations for screening (Studies #15 and #16).

Principle 8: Disseminated Results to all Partners and Involves Them in Wider Dissemination of Results

Much of the final year’s activity for RACDP was focused on dissemination of results. To assure access to findings from the twenty separate studies, an overview of each study was summarized in paragraph form and then again with listing of individual findings. These are included on the Program WEB site and included as opening files on the compact disk prepared for dissemination. Study #18 provides a summary of comments from a number of community leadership groups to which the findings of RACDP were presented. These groups included regional public helath, clinical care, academic and governmental leaders. Additionally, Study #20 provides copies of presentations made to policy making bodies about findings. Finally, the Community Cancer Research Review Work Groups represent another method employed through which community members were presented findings an asked to share those findings within their own communities.

Principle 9: Involving a Long-Term Process and Commitment

Through the RACDP, many different partnerships were forged between the community, the organizational sponsors and other cancer control efforts across Central Appalachia. Throughout the twenty objectives, partnerships with the community and all partners involved remained intact. In some objectives, even certain community leaders forged partnerships with state agencies. In Study #19, two of the members now are affiliated with state-wide cancer coalitions. Also, many of the communities that were involved
with the RACDP have participated in more than one project. Because of reservations, trust is hard to achieve between academic research and communities in central Appalachia. Through participation with the RACDP, trust has been established and these partnerships will continue with projects in the future.

**CONCLUSION**

The RACDP used many methods to explore cancer disparities in Appalachia. Community-based participatory research has served as an important philosophy and framework for the Program’s efforts to successfully examine these disparities. CBPR has served as an effective method to use with the Appalachian population. Cancer is an important issue to the communities in Appalachia. What was learned from the endeavors of the RACDP will aid in the shaping of future research questions as well as change the way cancer is studied, communicated, and viewed in Appalachia. Through the use of CBPR, the RACDP not only developed relationships with communities, agencies, providers, and other organizations but it also facilitated the development of relationships between rural communities and state agencies, an important precursor to improving the health of rural communities.
REFERENCES


