

Session 5 Outcomes: Cancer Research Work Groups

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ABSTRACT

East Tennessee State University and its partners promoted the use of community-based participatory research through the Rural Appalachian Cancer Demonstration program. Two Community Cancer Research Review Work Groups were formed in Spring, 2006 in Northeast Tennessee and Southwest Virginia to include community members with extensive social networks. Qualitative and quantitative findings about cancer in the mountains were presented to each work group in four presentation and discussion sessions. Each work group member was challenged to develop his own "Session 5" activity to further disseminate findings they felt important for those in their social networks. The results of Session 5 activities were varied. Information and findings that rural Appalachians thought was important was identified. Work group members clearly were willing to act as dissemination agents of cancer information and multiple rural approaches to dissemination were identified. The Work Group approach was also successful in engaging rural community members in state cancer control plans and promoting interest in further obtaining information and promoting community action.

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BACKGROUND

The Rural Appalachian Cancer Demonstration Program (RACDP) was funded by a Congressional appropriation through the Centers for Disease Control and Prevention to East Tennessee State University beginning in 2001. With partners in Tennessee (ETSU), Virginia (LENOWISCO Health District) and Kentucky (Markey Cancer Center at the University of Kentucky), the grant was to explore, identify, describe and document cancer disparities in the Appalachian regions of the three states. The program supported a number of separate but related research projects from 2002-2005. The community based participatory research (CBPR) approach was used for multiple projects, emphasizing the role of communities in identifying issues, participating in research, and confirming researchers' findings. Community Research Review Work Groups were formed in rural East Tennessee and Southwest Virginia to continue this CBPR approach. The Work Groups consisted of grass-roots community membership. Their purpose was to review and consider RACDP findings from a community member perspective. A second purpose was to understand how Review Work Group members could use their social networks to disseminate findings about cancer disparities to their communities in Appalachia.

Grass-root community representatives were recruited to serve on two Work Groups. The Work Groups purposefully included no practicing clinical providers as members. Members occupations varied (e.g., teachers, librarians, community cancer advocates, housewives, retirees, etc.) and the groups included a number of cancer survivors and family caregivers of cancer patients. The group in Northeast Tennessee included twelve representatives from seven counties. The group included members of rural Appalachian communities including Whites, African-Americans, and Hispanics. The Southwest Virginia group was more homogeneous with 10 members from two counties. A small hourly stipend was paid to members to compensate for lost work time and travel. The Tennessee group met in Jonesborough and the Virginia group met in Wise.

Four Work Group sessions were conducted in March and April, 2005. The time commitment of Work Group members was extensive. Each Work Group met four times for two hours each session. The topics (see Table 1 below) were planned to cover the results of the RACDP findings. Each of the first four meetings included an educational component to address key program elements: a level of comfort and literacy about health statistics, health behavior and communication theory, and the continuum of cancer care within communities and the health systems. Each meeting included a presentation by a thirty minute resource person that integrated program findings followed by a sixty minute facilitated discussion. Work Group facilitators were ETSU faculty members (a PhD Nursing professor and a PhD Health Communication professor). ETSU graduate students acted as recorders. Each session was audio-taped and transcribed verbatim. Results of the overarching themes generated through the Work Group sessions are reported elsewhere.

The process in which the information was disseminated to participants was carefully executed in order to avoid overloading the participants with data. First, the participants listened to a 30-minute presentation about certain issues regarding cancer in Appalachia. After the presentation, the participants were given 90 minutes to discuss the information that they heard and answer questions asked by the focus group facilitators. The members were given a copy of the presentation to read over later and share with others. They were also encouraged to contact the facilitators with any additional questions that they might have. At the end of the first four sessions, a CD with all presentations as well as both state cancer plans was also distributed to the participants for further review as well as to help them prepare for Session 5. Because of the amount of information given; this method allowed time for the group to become more familiar and somewhat comfortable with the data. This method was beneficial because it allowed the participants to process the information collectively and decreased information overload.

Table 1: Outline of Work Group Sessions

Session	Intent	Resource person
1	Introduce health disparities findings from RACDP and ARC studies	-Staff -Public health epidemiology speaker
2	Discuss communication issues raised by RACDP studies	-Cancer communication expert
3	Introduce research methods and human subjects protection	-Researcher with IRB experience
4	Present elements and process of State Cancer Plan and identify ways communities can become involved	-TN Cancer Coalition member
5	Disseminate findings through community meetings organized by Work Group members in their own communities	Staff assistance to Work Group members
6	Review overall research and disparities findings and summarize	RACDP principal investigators

For Session 5, each Work Group member was asked to organize and conduct a dissemination event in his/her own community to share information learned through the Work Group sessions about cancer disparities. Facilitators did not dictate dissemination session format, content or timing. Each member was provided any information or data that they requested. This approach was designed to identify:

1. How rural Appalachia social networks might be tapped by local leaders to distribute cancer messages
2. Which cancer messages were seen as most important to Work Group leaders and to their communities
3. What dissemination methods are used by Work Group members to reach their communities

FINDINGS

The intent of Session Five was to maintain alignment with the precepts of community based participatory research, helping the program to understand the roles of social networks for diffusion of messages in rural Appalachia. This project was very successful at using a grassroots approach to disseminate information about cancer in Appalachia. The involvement of community leaders facilitated entree to communities through existing social networks that might otherwise have remained off limits to professionals. Many of the workshop participants in each of the Tennessee and Virginia groups collaborated in their efforts in order to reach broader target audiences. In total, 16 of the 24 work group members participated in any Session Five event. Analysis of the events resulted in the following themes:

1. Community and professional networks were most widely used in dissemination.
2. The most common message used by Work Group members was the regional excess mortality rates for cancer.
3. More Work Group members chose to disseminate messages using interpersonal or face-to-face communication (e.g. panels and presentations) rather than written information (fact sheets, reports, pamphlets).

Dissemination activities were varied. These included creation and distribution of informative documents, drafting of letters or newspaper articles, presentations to community meetings, staffing information booths, and gaining membership to statewide cancer coalitions. Almost all participants used specific information learned in the first four sessions. Eight of the twenty-four participants conducted presentations to pre-existing groups in their communities. Seven participants created and distributed informative pamphlets, posters, and fact sheets. Three participants engaged in community meetings regarding cancer, while two participants shared information as part in various community health- related events.

One type of information that attracted participants were maps regarding cancer mortality. The maps represented differences in mortality statistics and members felt that this type of information would be the best way to reach their communities. Twelve of the participants utilized their professional networks to disseminate information. For example, one participant planned a presentation with co-workers. Another used his position as a teacher to disseminate the information to students and other faculty. Eleven of the participants used community networks to disseminate information. One participant wrote a letter to the regional cancer center urging hiring of an advocate for cancer patients. Another community networks that was tapped by three members was community churches. Three used family networks to disperse the information, for example, posting informative posters about cancer in his business.

Individual involvement levels were reflective of many Appalachian community engagement activities. Group attendance for the four sessions was high, but a few members failed to participate in Session 5 due to family illness or death and other life

and work priorities. Several participants were caregivers for family members with cancer during the project. Some group members did more than others in pursuing their personal Session 5 activities. These members had personal or familial connections with cancer (e.g. survivor), were already involved in cancer-related volunteer work, or had a high degree of self-efficacy in educating others on the subject of cancer. Others were less aggressive in their pursuit of action, expressing a lack of experience or a lack of a sense of success in educating others on cancer and related issues.

Work Group members identified that their communities were not seen as “joiners”. That is, there are not a lot of collective community efforts to address issues like cancer. However, group members stated in community communication logs that an amount of the information was informally disseminated through family networks, which remain an important part of culture and society in Appalachia. These discussions with family help to reshape the content of cancer messages distributed throughout the community and stress the importance of prevention among the community members. Participation in the Work Group and dissemination of cancer messages through interpersonal channels was seen as natural and reached many who would not have readily been contacted through other community-wide events or channels.

Another outcome of the project was an increase of awareness about state cancer plans. Before the project, there was limited knowledge about state cancer control plans. Through session 4, the participants not only became aware of the plans, they also received an opportunity to discuss them with state cancer plan representatives. After this session, many of the participants from both groups inquired about obtaining extra copies of the plans to disseminate among family members and others in the community. Subsequent to their involvement in the Work Group, one member from Virginia was invited and joined the state cancer control planning committee. Another Tennessee member was invited to present to the Tennessee Comprehensive Cancer Control Coalition’s annual meeting.

CONCLUSIONS

Cancer research review work groups are an effective method to engage community participants in learning more about cancer and disseminating cancer control messages into rural communities. In a region often cited as difficult to reach because of its rural geography, generally lower educational achievement statistics and sense of being closed to outsiders, the use of community members with rich personal social networks demonstrates a practical means of entrée and message dissemination. The Work Groups project was planned to promote new personal learning, with presentations, facilitated group discussion and questioning of regional cancer statistics and issues. Each state group bonded with a sense of common purpose. Two-thirds of members willingly used their own social networks to personally disseminate cancer control messages. The project demonstrates the use of the precepts of community-based participatory research process to effectively engage and involve communities in cancer issues.

Summary of Outcomes from Session Five Community Work Group Activities

Member Code	Description of dissemination activity	Which social network was used to disseminate information?	What data/concepts were used?
VA01	[Planned] Presentation to co-workers	Professional Network	TBA
VA02	[Planned] Presentation to local Lions Club	Personal Network	TBA
VA02	[Planned] Informational posters at local lawnmower shop to target men.	Family Network (family owned business)	TBA (High cancer-related morbidity and mortality in Appalachia)
VA02	[Planned] Presentation to local quilting group	Personal Network (Membership in group)	TBA
VA03	[Completed] Letter writing campaign to regional cancer center regarding the hiring of a patient advocate	Personal and Professional Network (addressed to VA03's Oncologist)	-Need to improve healthcare provider-patient communication throughout cancer continuum
VA 04	[Completed] Presentation to local nursing students and faculty (collaborated with VA 07, 08, 09)	Professional Network (used health educator role to coordinate outreach project)	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP research findings (e.g., barriers to breast cancer screening)
VA04	[Completed] Participated in radio segment regarding cancer	Community/Professional Network	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia
VA 05	N/A		
VA 06	N/A		
VA 07	[Completed] Presentation to local nursing students and faculty (collaborated with VA 04, 08, 09)	Professional Network (used health educator role to coordinate outreach project)	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP research findings (e.g., barriers to breast cancer screening)
VA 07	[Completed] Pamphlet for	Community and Family	- High cancer-related

	distribution at local community center and employment offices (collaborating with VA 08)		morbidity and mortality in Appalachia - Describe and document cancer disparities in central Appalachia - Review RACDP ongoing projects and goals
VA 08	[Completed] Presentation to local nursing students and faculty (collaborated with VA 04, 07, 09)	Professional network (used health educator role to coordinate outreach project)	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP research findings (e.g., barriers to breast cancer screening)
VA08	[Completed] Pamphlet for distribution at local community center and employment offices (collaborating with VA 07)	Community and Family	- High cancer-related morbidity and mortality in Appalachia - Describe and document cancer disparities in central Appalachia - Review RACDP ongoing projects and goals
VA 09	Presentation to local nursing students and faculty (collaborated with VA 04, 07, 08)	Professional network (used health educator role to coordinate outreach project)	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP research findings (e.g., barriers to breast cancer screening)
VA 11	N/A		
VA 12	[Completed] Letter to the Editor/local newspaper	Community	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP ongoing projects and research goals
VA 12	Joined cancer plan action group (state level organization)	New membership in statewide organization	-To represent regional concerns about cancer disparity.
TN01	[Completed] Community	Community, Family, and	-information gained in WG

	Meeting at local church (collaborated with TN12)	Professional Networks	sessions -cancer disparities data - Reviewed RACDP research findings
TN02	[Completed] Booth at Washington County Relay for Life	Community and Professional Networks	-cancer disparities data - Reviewed RACDP research findings
TN03	N/A		
TN04	[Completed] Participated in radio segment regarding cancer	Community and Professional Networks	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia
TN05	[Completed] Community Presentation	Community and Professional Networks	-cancer screening resources -cancer disparities data
TN06	[Completed] Information booth at church block party. (collaborated with TN07)	Community and Professional Networks	-offered cancer screening resources information -presented cancer disparities data from WG
TN07	N/A		
TN08	[Completed] Gathering of individuals from NE Tennessee Hispanic Ministry and Knoxville Hispanic Ministry	Community Network	Ongoing workgroup to identify treatment avenues for Hispanic community members following free screening in the community
TN09	[Completed] Community Health Fair	Community and Professional Networks	Offered information about cancer disparities in addition to free cancer screening resources
TN10	[Completed] School-based cancer information session	Community and Professional Networks	-information gained in WG sessions -cancer disparities data - Reviewed RACDP research findings
TN11	[Planned] Newspaper article describing cancer research review workgroups	Community Network	- High cancer-related morbidity and mortality in Appalachia - Described and documented cancer disparities in central Appalachia - Reviewed RACDP ongoing projects and research goals
TN12	N/A		