

***The Cancer Message:
A Workshop on Health Communication Issues***

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RURAL APPALACHIAN CANCER DEMONSTRATION PROGRAM

ABSTRACT

This workshop was held as part of a larger effort to explore and better understand cancer disparities in the Appalachian region of Kentucky, Virginia, and Tennessee. Recent research in Appalachian communities in these three states had indicated that communication was a significant issue in all aspects of cancer prevention and control. The workshop was held to further explore cancer communication in this region, and how that might contribute to Appalachian cancer disparities.

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OVERVIEW

Thursday, April 24: We invited community members and health care providers who were interested in issues around cancer communication in Appalachia to join us for a day of interactive small group sessions around some common cancer messages we heard in local communities. These messages included statements such as “*Clinical trials are experiments – they’re going to try something and they don’t know if it’s going to work or not*”, “*Chemicals in food and in the air cause cancer, I don’t have any control over that*”, and “*No one survives cancer, I don’t know any survivors*”.

These participants used a small group format to explore questions of: 1) how can we communicate better about cancer in Appalachia? 2) How can each of us be more effective senders and receivers of cancer information?

Friday, April 25: We invited a small group of Thursday’s participants to join us for a working group session the following day. Participants included representatives from across the cancer prevention and control continuum, including researchers, community and state agency representatives, oncology physicians and nurses, patient educators, media specialists, CDC representatives, and public health.

This group explored questions of: 1) what key findings about cancer communication in Appalachia emerge from the Thursday workshop? 2) How can we apply these findings in research and implementation efforts to improve Appalachian cancer outcomes?

WORKSHOP OBJECTIVES

The workshop was intended to be an active learning and sharing experience amongst diverse participants. The centerpiece of our methodology was the small group sessions. Each session addressed a particular statement, a common cancer message we had identified in our earlier community based research. Key principles in the design were: 1) everyone is a sender and receiver of cancer information, so everyone is an expert, and 2) we are missing a lot of knowledge in this area, so our primary interest is in creating opportunities for new information to emerge.

The statements were used to drive a loosely structured two hour session involving discussion of the statement and recommendations for addressing some of the underlying communication issues:

1. Sessions began with providers and community members splitting up to discuss their statement. For example, the group discussing “*Clinical trials are experiments – they’re going to try something and they don’t know if it’s going to work or not.*” had separate conversations about what providers and lay people associate with words like “clinical”, “trial”, “randomized”, and “placebo”.
2. Then groups blended back together, shared their key discussion points, and heard from some community and provider experts, who added new information to the conversation. For example, the group discussing “*Radiation will cook you – the treatment is worse than the disease*”, heard from a cancer survivor about her radiation therapy experience, and from a radiation oncologist about recent improvements in radiation therapy.

3. Last, the groups each tackled a particular exercise to develop specific, practical recommendations and tools for improving communication on their topic. For example, the group discussing *“People don’t get screened because the tests are embarrassing or uncomfortable”* critiqued national educational and advertising materials for mammograms and colorectal screening, commenting on their likely effectiveness in Appalachian communities.

As a comment on the risks of any experimental undertaking, about half the sessions proceeded basically as expected. The other half deviated in some major way, although participant feedback from these sessions indicated that the group experiences were still very valuable. We will be developing a more formal evaluation of what worked well and what might need to be altered in future exercises of this nature.

SUMMARY PRINCIPLES

At the end of the Thursday sessions, participants came back together in a large group format and shared key principles that they felt would improve communication about cancer in Appalachian communities. These key principles represent a summary consensus based on both provider and community input.

- ✓ Stress two-way communication and dialog.
- ✓ Recognize and stress the needs of individuals.
- ✓ Emphasize that it is okay to ask questions and create an environment that fosters this.
- ✓ Work from the patient’s knowledge base; don’t assume knowledge because of educational level.
- ✓ See patients as part of the interdisciplinary team.
- ✓ Give patients time to process thoughts and ask questions.
- ✓ Gain sense of awareness of culture, language, and expectations.
- ✓ Listen from the heart to the stories.

EVALUATION AND FEEDBACK

This workshop was designed to test some innovative approaches to exploring cancer communication in Appalachia. We were therefore very interested in participant feedback and reactions to the often experimental formats over the two days. Our evaluation, based on both formal and informal feedback:

- ✓ We opened the Thursday workshop with a dramatic presentation by Life’s Circle, a local group which uses a storytelling approach to share cancer survivor experiences. The inclusion of Life’s Circle was commented on many times, very favorably. Their presentation set a wonderful tone, and highlighted the practical importance of the issues we were discussing at the workshop. CDC is interested in having Life’s Circle come to their September cancer conference.
- ✓ The blend of community members, practicing health care providers, and agency health professionals was unusual, and well received by the participants. Many commented that even more community participation would have been welcome
- ✓ The small group methodologies were seen as innovative and valuable by participants. Even when the groups did not closely follow their outline, or did not complete all the steps in the

process, feedback was excellent. Several participants commented that these were some of the most useful conference sessions they had attended in years.

Overall, we believe the interactive format and innovative methodology of the workshop were quite successful, and a reference point for future joint learning initiatives with providers, community members, and research programs.