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Community Members' Input into Cancer Prevention Campaign Development and Experience Being Featured in the Campaign

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Abstract

Background—Colorectal cancer (CRC) incidence and mortality rates are increased and CRC screening rates are lower among Appalachia Ohio residents.

Objectives—We sought to describe 1) a partnership of cancer researchers and community members that developed county-specific media campaigns to improve CRC screening rates (intervention) and fruit and vegetable consumption (control) and 2) the experience of community members featured in the campaigns.

Methods—Community members assisted with campaign-development, were featured in campaigns, identified locations for materials, and promoted the campaigns. Campaigns included billboards, posters, and information in local newspapers. A mailed survey assessed featured community members' experiences in the campaigns.

Lessons Learned—Ongoing communication among members of the partnership was critical to successful community-level campaigns. Featured community members had mostly positive experiences about being included in the campaigns.

Conclusions—Having a shared vision, ongoing trust, and good communication are essential elements to maintaining a viable academic-community partnership.

Keywords

Health disparities; Health promotion; colorectal cancer; Appalachian region; Rural population

In the United States, CRC remains the third most common cancer diagnosed and the second leading cause of cancer death.¹ CRC incidence and mortality rates vary with population groups depending on race, ethnicity, and geographic location.² One population group with

excess CRC burden is Appalachia Ohio residents. The CRC incidence and mortality rate among Appalachia Ohio residents (2000–2004) was approximately 17% higher than the U.S. rates.³ A contributing factor to the increased CRC rates among Appalachia Ohio residents is lower CRC screening rates.^{3,4}

Reasons for lower CRC screening rates are barriers at the patient, provider, and system levels. Patient barriers include poor knowledge, limited access to health care, lack of provider recommendation, no health insurance, fear, embarrassment, inconvenience, test preparation, perceived discomfort/pain, and transportation issues.^{5–10} Provider barriers include reluctance to order CRC screening tests owing to cost or perceived patient barriers, lack of agreement with screening guidelines, and competing priorities.^{11–17} The lack of a chart reminder system or policies to improve screening rates are identified system-level barriers.^{10,17,18}

One strategy to encourage behavior change is media campaigns, because of their appeal, wide reach, and cost effectiveness.^{19,20} The success of campaigns has varied, partly because of difficulty assessing the population's exposure to campaign messages.^{21,22} Media health campaigns have been shown to work when they are theoretically based, use multiple channels, promote a specific health topic, are used in conjunction with other intervention strategies, and achieve reasonable levels of message exposure with the target audience.¹⁹ Successful health campaigns increase the amount of information on a topic above what is available in the natural course of events, and frame the topic to make it attractive to the target audience.^{23,24}

Based on the wide reach of media campaigns and a request from Appalachia Ohio community cancer coalition members to academic researchers at The Ohio State University (OSU) to address the CRC burden in their local communities, we partnered to develop county-level campaigns to improve CRC screening rates. Because community members were not in favor of a pure “control” group, our partnership developed a campaign to address low fruit and vegetable consumption among residents in the control counties.⁴ The purpose of this paper is to describe the lessons learned during the development and implementation of community campaigns to help inform future cancer prevention and control campaigns.

METHODS

Partnership

The partnership of OSU cancer researchers and five cancer community coalitions located throughout Appalachia Ohio has existed for more than a decade. The partnership, the Ohio Appalachia Community Cancer Network, has an advisory board composed of coalition members, community-based organization representatives, cancer survivors, and academic researchers. The board meets quarterly by telephone or in person, and a staff member attends monthly coalition meetings to address community concerns, provide updates on current projects, discuss opportunities, and support ongoing communication. Coalition members identified the increased CRC rates as a concern among community members. Based on this concern, OSU researchers and coalitions partnered to develop county-level campaigns, and to plan for study implementation and evaluation. Because the campaigns featured

community members, we thought it was important to evaluate the experiences of the featured community members as a component of the process evaluation. Community members serving on the study advisory committee agreed with the importance of process evaluation, provided input about the interpretation of results, and were asked to assist with writing and editing of the manuscript.

Campaign Development

Previously, our academic–community partnership completed a pilot study that successfully developed, implemented, and evaluated a CRC screening campaign conducted in one Appalachia Ohio county.²⁵ Based on the positive experience and findings, we designed a county-level, randomized trial to evaluate a campaign to increase CRC screening rates. The pilot study's results suggested that a campaign in Appalachia should include billboards, posters, and local newspaper articles featuring community residents.

Before finalizing the plans for the campaign names and messages, component options, and plans for distribution of campaign materials throughout the region, we conducted focus groups with assistance from coalition members. The focus groups provided input about barriers to CRC screening and fruit and vegetable consumption in their communities. Barriers identified by focus groups corroborated information from coalition members and included limited access to health care and fresh fruits and vegetables, lack of knowledge about the importance of completing CRC screening and eating fruits and vegetables, privacy issues, transportation, and poor patient–provider communication. Additionally, community members provided valuable input into campaign material content including message design, channel(s) to reach the community, and a plan to implement the campaigns. For example, community members suggested that all materials include a toll-free number so community members could call to receive county-specific locations to complete CRC screening or purchase fruits and vegetables.

The theoretical foundation for the campaigns was the Social Cognitive Theory (SCT).²⁶ The SCT posits that there is interaction among individuals, their environments, and their behaviors. SCT provided a structure for message creation that models desirable behaviors and teaches skills necessary to enact the behavior (e.g., observational learning by exposure to media displays: “Talk to your doctor or nurse about CRC screening”).²⁶ Additional SCT constructs addressed by the campaigns were reciprocal determinism (behavior promotion by campaign materials), self-efficacy (improving beliefs about ability to discuss CRC screening), collective efficacy (community members advocating for improved community health), facilitation (providing a toll-free number to connect community members with local resources), and self-regulation (enlistment of social support). We thought that by using community engagement in the campaign design and by featuring community members in the campaign materials, the discussions among community members would increase issue salience.

To test campaign effectiveness, counties were stratified based on average percent late stage of CRC at diagnosis to create three strata of four counties each. Within each stratum, the four counties were randomized to two intervention and two control counties. This process resulted in six intervention counties receiving the CRC screening campaign, entitled *Get*

Behind Your Health (GBYH). This campaign focused on a cue to action by activating community members (50 years old) to discuss CRC screening with their health care provider. The campaign message was: "Colon cancer screening saves lives. If you are 50 or older, talk to your doctor or nurse." The six control counties received a campaign to promote fruit and vegetable consumption entitled *PEACHES* (Promoting Education in Appalachia on Cancer and Healthy Eating Styles). The campaign message was "Be healthy. Eat fruits and vegetables."

The year-long campaigns included one billboard per county, 120 posters located throughout the counties (number varied based on population, with a minimum of five posters per county), and a media kit for local newspapers. The GBYH campaign featured CRC survivors, community members who had completed CRC screening, health care providers, and cancer coalition members. Local farmers, owners of local produce stores, and cancer coalition members were featured in the PEACHES campaign. The posters featured the same community residents and included a short, personal narrative provided by the residents. Community members identified locations with high visibility for campaign materials and assisted with featuring the campaigns in local newspapers.

Featured Community Members

Each county resident identified by the coalitions was invited to participate in a campaign. A research team member contacted each potential participant and explained the purpose of the campaign. A team member met with community members willing to participate to obtain short testimonials and pictures to include in the campaign materials. After the campaign, a survey was mailed to adult community members to gain insight into their experience of being featured in the campaign. The researchers and coalition members thought that experiences of the featured community members would be valuable in understanding community campaigns and to inform future campaigns.

The survey included open- and close-ended questions, including demographic characteristics (age, gender, education), personal and family history of CRC (yes, no), CRC screening status (50 years old) including type of test (fecal occult blood test or colonoscopy) and time since completion of last CRC screening test (past year, past 5 years, past 10 years, or do not remember), perceived comparative risk of CRC (much below to much above average risk), daily fruit and vegetable consumption (0–1, 2–3, 4–5, 6 servings), billboard or posters seen by self (yes, no) and others (1–3, 4–6, 7–9, 10 people), types of people who discussed health behavior or campaign with participant (family, friend, neighbor, co-worker, customer, patient, community member that they did not know, nurse, doctor, other), participants' confidence in discussing the health behavior and/or campaign (strongly agree to strongly disagree), and participants' agreement with the message on their billboard or poster (strongly agree to strongly disagree).

We used data collection procedures to maximize survey response rate.²⁷ A letter was mailed explaining the study and asked featured community members to complete the survey being mailed in a few days. A cover letter, survey, and a stamped, addressed reply envelope were mailed to participants. Two weeks later, a letter was mailed that thanked those who returned the survey and reminded those who had not completed the survey to return it soon. One

week later, a replacement survey and envelope were mailed to participants who had not returned the survey. This study was approved by the OSU's Institutional Review Board.

Data Analysis

Descriptive statistics provide characteristics of the featured participants. Demographic characteristics of participants in the different campaigns were compared using the *t* test (mean age) and chi-square tests. Additionally, chi-square tests were used to determine differences in categorical variables. Statistical tests were completed with SPSS Statistics 20 software. Open-ended questions were coded and summarized for qualitative analysis.

RESULTS

Seventy adult community members were featured in the campaigns. The current address for three community members was not available, resulting in 67 individuals (20 GBYH; 47 PEACHES) being sent a survey. Returned surveys ($n = 50$) resulted in a response rate of 75% and did not differ significantly by campaign or by campaign material (billboard vs. poster).

There were no differences in participants' age, gender, or educational level by campaign (Table 1). Five GBYH participants reported a personal CRC history compared with one PEACHES participant ($P < .05$). Eleven participants reported a family history of CRC, with no significant difference by campaign. Among average-risk participants (no personal or family history of CRC), 8 were in the GBYH campaign and 27 in the PEACHES campaign. Average-risk participants reported their perceived comparative risk for CRC as being below average ($n = 12$; 34%), average risk ($n = 15$; 43%), above average risk ($n = 6$; 17%), and 2 (6%) participants reported not knowing their CRC risk. Among participants aged 50 years or older ($n = 34$), 29 (85%) reported CRC screening within recommended guidelines. Fruit and vegetable consumption was poor, with 33 participants (66%) reporting consuming fewer than five servings of fruits and vegetables daily.

Thirty of the 50 participants were told that their billboard or poster was seen by a community member (Table 2) including friends ($n = 22$), family members ($n = 18$), co-workers ($n = 12$), and customers ($n = 11$). Among participants, 40% reported that they thought the campaign influenced behavior change in their community, and most participants reported that they liked talking with community members about the campaign and wished that more people had discussed the campaign (Table 3). Many participants (66%) reported that they would agree to be featured in future media campaigns so that they could promote the importance of CRC screening or eating fruits and vegetables, because the experience was good publicity for business, and that they wanted to help their community. Reasons for not wanting to participate in future campaigns included having a preference for working behind the scenes, not thinking there was enough interest generated by the campaign, and not liking their picture on campaign materials.

DISCUSSION

The academic researcher and Appalachia Ohio community coalition partnership developed media campaigns that are being evaluated in a county-level, randomized trial. Although the primary outcome of the campaigns is not known, we learned valuable lessons about working together to develop and implement the campaigns.

The first lesson we learned was the importance of reaching beyond the partnership for advice about campaign materials. Community members who participated in focus groups assisted with refining the campaign messages and suggested locations for campaign materials in the various counties.

Another lesson learned was the difficulty associated with purchasing billboard space in desired locations and within the study's time period. In a few counties, we had to use a billboard close to the recommended location because of the limited availability and small number of billboards located in rural counties. Often, we found that the recommended billboard locations were purchased for multiple years in advance and we would not have access to the suggested billboard location. Another example of problems associated with limited numbers of billboards occurred early in the campaign period. One billboard was defaced by vandals, and community members wanted immediate replacement of the billboard. The billboard was replaced (with additional costs) in a few days; however, we had to relocate to a different billboard near the suggested location so it could not be reached from the ground. Thus, although we attempted to locate the billboard in the high-volume location suggested by community members, sometimes it was not possible.

A very important lesson learned was the value of ongoing communication with the featured community members in addition to our established community partners. Although we placed posters in county locations suggested by community members in our partnership, some featured participants mentioned other places where they thought the posters would reach more community members. We also learned the importance of checking the spelling of individuals' names more than once. Unfortunately, two featured members had their names misspelled on campaign materials; thus, attention to detail is critical when involving community members in projects.

Other lessons learned were the importance of checking on the campaign materials throughout the campaign period and the costs associated with conducting process evaluation and replacing campaign materials. We conducted monthly checks on the campaign materials and found that store employees sometimes moved posters, the poster was covered by other materials or was damaged, and featured community members removed their poster before the end of the campaign. An important recommendation would be to budget for replacements for campaign materials and to budget for additional travel costs associated with routinely checking on the campaign materials.

Although we learned valuable lessons from partnering with the community on the development and implementation of the campaigns, there were many positive experiences reported by community members. Engaging the community in research provided the opportunity for the development of culturally appropriate interventions and improved

success of the research.²⁸⁻³⁰ Although engaging the community suggests a collaborative process, in practice, community members do not typically participate in all aspects of the research process as much as the academic partners.^{31,32} Previous research suggests that the stages of research with the highest rates of community member participation are selection of the research question, recruitment and retention of participants, intervention development and implementation, and study design. Community members participate less often in the grant development, analysis, interpretation and reporting of the findings, and financial responsibility for study.

One study focusing on community members' perceptions as partners in the research process identified barriers to successful partnerships, including community partners' lack of understanding of their roles in the research process, slow implementation of interventions, and lack of community recognition of the intervention name.³³ Another study of community members' response to community-based participatory research (CBPR) identified barriers to a successful community-academia partnership, including wariness of close-minded or patronizing university affiliates and skepticism that the research would lead to meaningful programs or policy changes.³⁴ These studies suggest that the CBPR process is imperfect and relies on communication and trust among community members and their academic partners to overcome barriers to productive outcomes.

Community media campaigns have been used successfully in the past to promote skin, cervical cancer, breast cancer, and CRC screening.³⁵⁻³⁷ An example of a successful CRC prevention campaign was conducted in Utah (2003) and used multiple media channels and local media talent as spokespersons.³⁶ In the 5-month study, there was an increase (from 36% to 79%) of individuals who reported seeing, reading, or hearing about CRC early detection in the previous three months, and among the 79% that had heard or seen an ad, 85% could recall one of the main messages of the campaign. This suggests that a CRC screening media campaign has the potential to improve CRC awareness, and possibly intent to get screened, and increase CRC screening rates in the future.

Well-planned, targeted media campaigns can affect health knowledge, attitudes, and even behaviors for a large number of people, and the CBPR paradigm could be utilized as a way to create campaigns that satisfy these criteria.³⁸ Targeting campaign messages by featuring community members, using culturally appropriate language, and emphasizing community values have proven successful in cancer prevention and awareness media campaigns targeted to different populations.^{39,40} Although campaigns can be effective at changing health behaviors, unfortunately there is limited evidence because many media campaigns are not evaluated rigorously.^{21,41} Reasons for poor evaluation of health promotion campaigns include the significant amount of resources and effort that are necessary to complete an evaluation for a large campaign, natural control populations are not always available to interpret the campaign's effects, and ultimately campaign evaluations are held to a weaker standard than other health intervention approaches owing to the operational and financial challenges of conducting evaluations of campaign.^{21,22,41}

Limitations of the study are that some featured community members did not complete the survey and may have had different experiences than the community members who returned

the survey. However, although the sample is small, our return rate of 75% is fairly good for a mailed survey. In addition, the survey used in this study was not a validated instrument. The generalizability of our findings to individuals featured in campaigns in other geographic locations or in campaigns focused about other health topics is unknown. Future research is needed to determine whether potential differences would be experienced among featured participants in campaigns conducted in other geographic settings or about other health topics.

In conclusion, productive academic–community partnerships require ongoing communication and effort from all partners to successfully address community-level health problems. We believe that, by engaging community members, campaigns are more likely to be relatable to community members, and thus have a better possibility of having an influence on changing behaviors.

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Table 1Participant Demographic Characteristics by Campaign^a

Characteristic	GBYH (n = 17), n (%)	PEACHES (n = 33), n (%)
Mean age (y)	58.7	59.3
Gender		
Male	7 (43.8)	8 (24.2)
Female	9 (56.2)	25 (75.8)
Education		
High school or some college	7 (46.7)	8 (24.2)
College or graduate degree	8 (53.3)	25 (75.8)
Personal history of CRC [*]		
Yes	5 (29.4)	1 (3.0)
No	12 (70.6)	32 (97.0)
First-degree relative with CRC		
Yes	5 (31.3)	6 (18.2)
No	11 (68.7)	27 (81.8)

Abbreviations: CRC, colorectal cancer; GBYH, Get Behind Your Health; PEACHES, Promoting Education in Appalachia on Cancer and Healthy Eating Styles

^{*}
p < .05.

^aNumbers do not always add to 50 because of missing data.

Featured Participants Reporting That Community Members Saw Their Billboard or Poster

Table 2

Variable	GBYH (<i>n</i> = 17), <i>n</i> (%)	PEACHES (<i>n</i> = 33), <i>n</i> (%)
Community members told featured participant that they saw billboard or poster		
Yes	11 (64.7)	19 (57.6)
No	6 (35.3)	14 (42.4)
Number of community members who told featured participant that they saw billboard or poster		
1–3	1 (9.1)	7 (36.8)
4–6	3 (27.3)	5 (26.3)
7–9	2 (18.2)	2 (10.5)
10	5 (45.5)	5 (26.3)

Abbreviations: GBYH, Get Behind Your Health; PEACHES, Promoting Education in Appalachia on Cancer and Healthy Eating Styles.

Table 3

Comments From Featured Community Members

Campaign	Comment
GBYH	"I'd like to have a 'flyer' to hand out (in addition to the campaign poster) . . ." "More people in this area need to be educated and encouraged to get screened." "Please correct the spelling of my first name . . ."
PEACHES	"Next time you might try using social media in your campaign . . . I use the Internet to market my products, so it would be easy to share the poster with my customers." "Was nice to be recognized as a 'helpful' organization. And we look forward to helping you express the need for more fruits and veggies." "I think it made my market customers feel more confident in their market." "Billboard was obstructed by trees—hard to see."

Abbreviations: GBYH, Get Behind Your Health; PEACHES, Promoting Education in Appalachia on Cancer and Healthy Eating Styles.