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Shifting Community-Based Participatory Infrastructure from Education/Outreach to Research: Challenges and Solutions

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Abstract

Background—For 10 years, the Deep South Network for Cancer Control (DSNCC) focused on training and deploying community health advisors (CHAs) to promote cancer screening and healthy lifestyle through education/outreach activities. In 2009, the request for application (RFA) for renewal of the DSNCC required a controlled research intervention. Converting from education/outreach to research proved more problematic than expected.

Objectives—The objective of this article was to describe the challenges and solutions during this conversion and to describe the importance of education/outreach to community infrastructure.

Methods—This is a qualitative assessment of the challenges and solutions encountered in conducting a controlled weight loss trial in a community setting in which education/outreach had been the priority.

Lesson Learned—The DSNCC provides a model for overcoming the unique challenges of converting a longstanding education/outreach program into a controlled research program.

Conclusion—Although multiple challenges were encountered in conducting a community-based participatory research (CBPR) controlled trial, solutions were developed and the trial continues as proposed.

Keywords

Community-based participatory research; Infrastructure; Funding; Education; Outreach; Research

In 2009, the RFA for Community Network Program Centers issued by the National Cancer Institute (NCI) required a controlled research intervention. This was in contrast with previous iterations of the program from 2000 to 2010 that focused first on building community infrastructure and, secondly, on interventions focused more on education and outreach to promote cancer awareness related to age-appropriate cancer screening, tobacco control, and healthy lifestyle. In the DSNCC, the first 10 years of the program focused on recruiting and training mostly African-American lay women and men who were “natural helpers” as CHAs promoting age-appropriate cancer screening, recruitment of African Americans into clinical trials, increased physical activity, and healthy diets. The DSNCC also developed partnerships with more than 200 organizations within our targeted area

including the American Cancer Society, Susan G. Komen for the Cure Foundation, the departments of public health in Alabama and Mississippi, city councils, churches, social clubs, and work sites. To varying degrees, these partnerships provided resources and support for the education/outreach components of the DSNCC.¹ The promotion of these health activities was through education and outreach activities. The CHAs conducted these activities in 20 rural counties and urban areas of Alabama and Mississippi with greater than 60% African American residents and greater than 30% poverty levels.²⁻⁶ Significant reductions in breast cancer screening disparity in the Medicare population were demonstrated and evidenced-based program such as Body and Soul healthy lifestyle programs were instituted in multiple churches throughout the regions served by the programs.⁷ In addition, a *Walk Feel Alive* Program promoting physical activity was also begun in targeted underserved counties across Alabama and Mississippi.⁸

In 2010, the third iteration of the DSNCC required design and implementation of a randomized, controlled intervention in the community. This proved more difficult than expected and provided some insight into the complexities of academic institutions working with community volunteers and managing expectations, even when using a CBPR approach.

This article reviews qualitatively the challenges that were faced in converting staff and volunteers from conducting education/outreach programs to conducting a rigorous controlled research intervention.

METHODS

In response to the 2009 RFA, the DSNCC proposed a randomized, controlled trial. The process for conceiving, designing, and developing the controlled trial for the application in 2009 included representatives from the communities engaged the previous 10 years. The randomized, controlled trial for the DSNCC focuses on testing evidence-based strategies supporting weight loss among African-American women in the Deep South. Eight existing DSNCC counties with a history from our prior work of committed and well-trained staff, were all rural, and had similar demographic characteristics were selected for the trial. Counties were randomized to one of two conditions: 1) a 24-month, group-based weight loss program or 2) a 24-month, group-based weight loss program plus community-level strategies to support healthy eating and physical activity. The group-based program is evidence based⁹⁻¹¹ and involves 1 year of face-to-face meetings (weekly for 6 months, followed by two sessions a month for 3 months, then monthly for 3 months) and 1 year of monthly motivational telephone calls guided by evidence-based principles.¹² Field-based project staff facilitates the first-year intervention, and CHAs conduct second-year calls under the supervision of the local project staff. Local community-based groups in counties randomized to the community strategies component receive funding to implement one community-wide strategy to support healthy eating and one community-wide strategy to support physical activity. Although the exact interventions vary based on the assessed nutrition and physical activity needs of the community, local grantees must choose from a preselected menu of evidence-based strategies¹³ determined by the DSNCC.

These eight counties were identified as “research” counties. The remainder of the 12 counties that were part of the previous 10-year program continued as “outreach” counties. The outreach counties continue to promote age-appropriate screening and healthy lifestyles via education/outreach with more of a focus on individuals/geographic areas not reached in the previous 10 years of work. The research counties primarily focus on execution of the controlled weight loss program while attempting to maintain a minimal amount of cancer education/outreach.

RESULTS, CHALLENGES, AND SOLUTIONS

Community Health Advisor Challenges

All volunteer CHAs recruited into the program were trained and deployed as education/outreach-oriented health advisors promoting age-appropriate cancer screening and healthy lifestyles through individual, group, and organizational contact. Although the official name for our community advisors used from the beginning was Community Health Advisor trained as Research Partners (CHAs), the “research” component in the first decade was mainly simple data collection by the CHAs regarding their own activity related to cancer health promotion, such as number of contacts, number of outreach programs delivered, content of message, provision of services such as transportation, and referrals to Breast and Cervical Cancer Early Detection Program. They were not trained in research methodology, such as determining eligibility, administering validated survey instruments, data collection from multiple sources, or data management following explicit protocols, and were not required to focus attention to details often required in rigorous, controlled research trials.

Challenge 1—As we began to engage and train our CHA volunteers in the eight research counties, it became apparent that skill levels necessary to assist in the conduct of clinical trials were varied. This is certainly not unusual for a group of volunteers with varied education and skill levels as opposed to employees who are vetted for specific skills to conduct complex tasks and are usually required to have a certain education level before being employed. In addition, those volunteers who had the requisite skills required more training and ongoing supervision than was required for education/outreach activities related to promoting cancer screening and healthy lifestyles. In addition, a number of our CHAs who had been recruited 10 years previously were now into their senior years with less willingness to devote to training and the complexity of a controlled trial. Although we developed our controlled trial through a participatory process, neither the academics nor the community fully appreciated the intensity and extent of the training that would be necessary for our volunteers to assist with the research program. The elements and complexity of training for implementing a controlled research trial are different from the training required for education/outreach programs.

Solution 1—After discussions with our county coordinators and our volunteers at the community level, the roles of those volunteers who did not demonstrate the skills necessary and/or have the desire to serve as a research assistant were adjusted. These volunteers were placed in more of a supportive role, such as assisting with facility set up, participant check in, and meeting reminder calls and were not actively engaged in research assistant roles such

as determining eligibility, conducting participant recruitment and enrollment, participant follow-up, or data acquisition such as recording participant height/weight and review of the dietary intake/food diary. This adjustment, however, added to the burden of those volunteers who were able to be trained and wanted to serve as research assistants, as they were required to engage more research participants than originally intended. More time in training than was originally planned was required. This placed an extra burden on the central office staff, requiring more travel to the research counties for training and support. In addition, because of the variations in skill levels of the volunteers, the training had to be tailored more individually than originally planned and required adjustment to the training schedule which allowed for more one-on-one training time.

Challenge 2—Some of the CHAs in the research counties also expressed frustration at the lack of innovation imposed by the research project. In the previous 10 years, CHAs had been given freedom to plan and implement education programs and outreach activities based on the needs of the community or individuals from the medically underserved community. In addition, they could engage partners of their own choosing at the individual or organizational level to advance their mission of increased cancer screening and healthy lifestyles. The rigorous protocol requirements of the weight loss intervention trial limited the ability to engage other partners and to be creative in designing programs and activities. This is a valid concern and is not a surprise given the standardization necessary for a controlled trial versus the “freedom” and adjustments typical of community based participation in education/outreach.

Solution 2—The solution to this issue was continued education regarding the importance of the controlled weight loss intervention to the eventual health of the communities and the need for rigorous attention to the details of conducting a controlled trial. The research team stressed that although only 409 women were affected directly by the weight loss intervention in the research counties, the results of the trial could have far-reaching implications for the communities if successful and disseminated. CHAs were allowed to attend the intervention weight loss sessions as the “CHA Helper” to assist participants. In this capacity, they could assist with weight checks, and work with participants who had difficulty following instructions and other related duties, such as review of the weekly food diaries for completion and distribution of the participants’ incentives. This provided them with exposure to the weight loss intervention without being an active participant in the evaluation. The volunteers in the research counties eventually adjusted to the change from outreach/service to research, but open and frequent communication and education to increase the knowledge regarding the importance of the trial and its rigorous conduction was necessary. The CHAs were also encouraged to continue education/outreach where possible.

Challenge 3—The CHAs, particularly in the outreach counties and to some extent in the research counties, were frustrated by the reduced funding for education/outreach activities imposed by a significant portion of budget directed to research as required by the RFA. With this reduction leading to fewer educational/outreach activities and promotional materials, the CHAs were doubtful that they could continue to have the impact on the community that existed in the previous 10 years. Some CHAs also expressed a sense of loss of leadership,

because the leadership's focus was primarily on the research intervention as opposed to education/outreach. **Solution 3.** This challenge was partially overcome by our seeking other funding through organizations such as the local Susan G. Komen Foundation and other philanthropic sources to increase support for education and outreach. We also were able to leverage some funding through our collaborative partners such as the American Cancer Society and with in-kind educational support from the State of Alabama Comprehensive Cancer Coalition and the Breast and Cervical Cancer Early Detection Program. In addition, the CHAs themselves provided resources on their own for educational/outreach efforts. But the fact remains that these resources did not reach the level of the previous iterations of the network and the impact of the reduction of education/outreach funding on community behavioral changes and preservation of the infrastructure is yet to be determined. Leadership continued to stress the importance of education/outreach and to provide support to the extent possible given the focus on trial implementation.

Challenge 4—As noted, we expected that CHA volunteers could serve as research assistants. If a CHA could not or did not want to serve in this capacity, we were challenged with finding a role for CHAs in our eight research counties.

Solution 4—In addition to providing the opportunity to participate as a “CHA helper” assisting weight loss intervention participants as noted, we also allowed the CHAs to choose to be a research participant, if eligible. Only 17 of the 409 weight loss participants in the eight counties were CHAs. To avoid contamination, we will analyze this group of 17 separately and not include them in the final analysis, particularly if they have significant differences in outcome. We have ample sample size without these 17 to meet our power calculations.

Staff Challenges

Challenge 5—In addition to challenges faced with the volunteer CHAs, we also encountered new challenges with both our central and community-based staff in converting from education/outreach to rigorous, controlled research. From a central staff (university-based) standpoint, administering and overseeing two simultaneous programs, education/outreach and a controlled research trial was problematic. Eight counties conducting research where it did not exist before and maintaining the ongoing education/outreach program in the remaining counties with a reduced staff was indeed a challenge for the central staff. Similarly, some of the employed community-based staff were overwhelmed by the task of directing, leading, and supervising the volunteer CHAs while recruiting for and delivering an intervention in a rigorous research program.

Solution 5—The staff issues required significant readjustment. First, the central staff had to be realigned with changes in roles, which required new training and adjustment to working on two or more different projects at the same time. In the previous DSNCC, all of the central and local staff worked on the same activities within a similar timeframe, that is, education/outreach with similar programs in all counties. Extensive hands-on guidance of the central staff by the program director was also required. The program director, a very experienced and savvy leader, provided weekly, one-on-one direction and significant

oversight of the staff activities. This also included the program director constantly assessing each staff member's strengths and weaknesses to better position them to carry out the tasks at hand. The stress put on the central and community staff as a result of these issues led to some staff turnover in the central office. Our original research plan was to have local county coordinators (paid staff) play a major role in the delivery of the research intervention. However, we found that in some cases the community-level staff (county coordinators) was overburdened by the complexity of the controlled trial. We hired two regional coordinators to provide more direct contact with local staff and deliver the more intensive part of the interventions (weekly sessions). This allowed greater consistency in the intervention. We also realized the needs at the central office demanded greater attention to protocol adherence, overall project management, and so on, and hired a full-time research project manager to relieve the program director of many of the day-to-day details to focus on the overall administration of the entire DSNCC. Because the central office staff had to assume a much greater role in the research project than expected, we added two staff centrally to assist with both outreach and research. In other words, more of the workload related to the research project was placed on the central staff than was originally planned or budgeted. However, with the adjustment, the weight loss intervention research project is expected to be completed on schedule, despite the myriad of challenges in converting DSNCC education/outreach infrastructure to an infrastructure supporting a controlled clinical trial.

DISCUSSION

Although the DSNCC created a community-based infrastructure that we understood would eventually be utilized to support community-based controlled research, the shift from community-based education/outreach to CBPR with a controlled clinical trial as a major component of the DSNCC proved more difficult than expected. During the first 10 years of the program, the focus was assisting our hundreds of trained CHAs and our community partners to promote age-appropriate screening and general clinical trial recruitment in the first 5 years and healthy lifestyles in addition to screening in the second 5 years. The program did support multiple small pilot research projects funded through supplemental funding from the Center to Reduce Cancer Health Disparity of the NCI and other funding sources. These projects were conducted without significant difficulties because they were small, did not interfere with or change the major focus of CHA work, screening and healthy lifestyle promotion, and did not reduce funding for educational and outreach efforts. These were very short-term projects with a one-time, specific task that the CHAs could do in addition to their existing CHA activities. In the third iteration of this funding mechanism, the Community Network Program Centers required a controlled trial and directed a substantial proportion of the total budget to this activity. Given the size of our network, and the limited research budget, the controlled trial could be conducted in only eight counties. We encountered a number of issues and challenges that were not fully anticipated by the researchers or the community when we designed the controlled trial although the design of the trial for the application was participatory and included members of the community.

The key principles of CBPR, its place within different scientific paradigms, rationale for its use, and exploration of challenges are discussed in a review by Israel and co-workers.¹⁴ Others have written about the challenges of CBPR.^{15–20} The challenges faced by the

DSNCC are not different from those experienced by others in the broadest context. What is different about our challenges is that they arose after a decade of relationship building, development of a successful community health advisor training program, successful deployment of hundreds of trained CHAs promoting cancer screening and healthy lifestyle through awareness and education; participating in a program in which all counties were treated the same, implementing education/outreach programs only. The CHAs were not originally recruited and trained to conduct controlled trials. This success was then followed by a decision to implement a controlled clinical trial embedded in the community infrastructure previously designed for and focused on community education/outreach. The specific challenges and solutions have been discussed previously.

In the larger context of CBPR, several important lessons are embedded in our experience with the CNPC and are the major “take-home” messages. One, education/outreach regarding age-appropriate screening and the development of healthy lifestyles is a tangible asset for the community at large and for the CHAs in particular and to a large extent is the “glue” that holds the volunteer CHAs and the community together with a common purpose and mission. In other words, one could make the argument that it is the education/outreach activities that sustain a community infrastructure that then allows for utilization of that infrastructure for controlled interventions, albeit with challenges. In our case, challenges arose because we had to sacrifice or decrease education/outreach at the expense of research. This change was frustrating to the community and proved problematic to the academic community that had spent a decade building an infrastructure based on education/outreach. In the context of participatory research, discussion between funding agencies and the academic/community partners regarding the importance of education/outreach to maintenance of infrastructure and design and implementation of controlled research in such an infrastructure would likely be beneficial.

A second lesson uncovered in our experience with the CNPC are the challenges embedded in the difference at both the volunteer and paid staff levels in delivering education/outreach programs versus conducting a rigorous, controlled trial. Although we were able to retool/retrain both volunteers and staff, in retrospect conducting a controlled clinical trial may have proceeded with fewer challenges if new staff and volunteers were recruited and trained specifically for conducting the controlled trial while support for the staff and volunteers conducting education/outreach continued. This provided challenges and problems that were unanticipated by the researchers and the community representatives when the trial and its implementation were planned as part of the application for funding. Although we eventually found solutions and the clinical trial continues on timeline as proposed, our experience is a vivid reminder that working with the community is a constantly evolving process that requires on-going exchange of information and training at all levels and all of the principles of CBPR must be applied continuously. In fact, the infrastructure developed by the DSNCC now supports a number of large, externally funded research projects. The researchers and the community have in each case applied the lessons learned by this experience to the development and implementation of these new community research programs encountering far fewer challenges.

In conclusion, education/outreach programs are very important to the community and, to a large extent, provide tangible assets to the community and its members that promotes maintenance of infrastructure. Although community research is critically important to our advancement of knowledge, the academic and funding agencies should remain cognizant of the communities' need for education/outreach in building and maintaining community infrastructure that allows for and supports community based controlled trials.

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