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Training of Community Health Workers to Deliver Cancer Patient Navigation to Rural African American Seniors

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Abstract

Background—Rural African American (AA) seniors may experience significant challenges during cancer treatment. Previous research suggests community health workers (CHWs) can provide effective cancer patient navigation (CPN) support.

Objectives—To develop a Train the Trainers (TTT) program for CHWs in rural Central Virginia who would navigate local AA seniors with cancer and train their support persons to provide similar types of assistance.

Methods—We conducted focus groups with rural AA seniors, consulted with experienced CHW trainers, recruited and trained CHWs through a combination of online learning and distance education, evaluated the TTT via surveys and focus groups, and hired CHWs to the study team.

Results/Lessons Learned—Lessons learned from our TTT experience include the value of incorporating CHW trainers and trainees as full members of the research team.

Conclusions—Training should be accessible and flexible, providing trainees community-level resources and enriched educational experiences. Findings have informed a culturally tailored support CHW intervention to address cancer diagnosis and treatment needs for older rural AAs.

Keywords

African Americans; community health aides; education; nonprofessional; neoplasms; nursing; health disparities; health services for the aged; participatory research; community-based; rural health

Rural-dwelling AA seniors with cancer may experience significant challenges that can lead to disparities in cancer-related outcomes and overall quality of life.¹⁻⁵ There is a need for sustainable, culturally appropriate support for these seniors and their support persons within the communities they live in.⁶⁻¹⁶ Prior research has shown that CPN delivered by CHWs¹⁷⁻²⁹ can improve cancer-related outcomes, although this has never been tested in this population.³⁰ To promote sustainability, acceptability, and effectiveness of the intervention, its development should be guided by AA seniors in rural communities affected by cancer-related health disparities, and through inclusion of local partners on the research team.³¹⁻³³ This paper presents lessons learned from ongoing research designed to develop and test a CPN intervention for rural AA seniors with cancer and their support persons.

Background

The need for additional support for rural AA seniors in treatment for cancer was identified through a series of community-based focus groups with rural AA cancer survivors conducted before the development of this TTT program.^{15,35} Survivors perceived that patient navigation assistance provided by local CHWs could provide the types of support they needed. Use of CHWs in rural areas has been effective in outreach to seniors and assisting them to navigate health-related services. Because the contributions of CHWs have been associated with improved care access and cancer screening behaviors, in addition to reduced health care costs among minority groups,³⁶⁻³⁹ we believe that they can be an effective part of a cancer support intervention targeting AA seniors. Ultimately, we hope to identify essential CHW training components associated with positive outcomes for cancer patients and their support persons. Insights from this pilot project are expected to result in an effective TTT program for nurse-supervised CHWs who will assist rural AA seniors by providing direct CPN support to them and their support persons (Phase One) and who will also train enrolled support persons to provide this type of assistance (Phase Two). This program will be used in a larger study within the same community to determine the effectiveness of providing sustainable cancer navigation support for rural AA seniors. CHW trainees are invited and have agreed to continue to participate in future work as full members of the research team. This manuscript reports on findings from the Phase One CHW training, which have further informed development of Phase Two of the project.

Methods

The community partnership was established through the use of contacts previously developed by the principal investigator and faculty from the Center for Rural Health Research at the University of Virginia (UVA) and through the UVA community outreach program. Regional community contacts were solicited through the American Cancer Society (ACS) office, and further extended through study team members' participation in Relay for Life events and other ACS activities. Our staff have partnered with local health service agencies and cancer centers at multiple levels, and our CHWs have steadily increased these partnerships. Additional contacts were developed from investigator work with area churches in a previous study.^{40,41}

In 2009, two experienced CHW "super-trainers" from the Centers for Medicare and Medicaid (CMS) demonstration project, "Partnership for Healthy Seniors" were recruited as members of the research team to assist in the creation and delivery of the TTT program. These CHWs had received extensive prior training and testing through their involvement in the CMS demonstration project. Super-trainers, along with three nurses representing psychiatry, oncology, and case management, were involved in all aspects of training development and delivery. A total of five AA CHW trainee participants were recruited in central Virginia using contacts within the UVA Cancer Center, local chapters of the ACS, and word of mouth. Participants had to meet the following criteria: (1) age 18 or older, (2) willing to participate in a training program related to working with older adults with cancer, and (3) residing in a rural area of Virginia. This site was chosen because of prior work in the community.^{15,35} Recruitment was conducted through flyers and advertisements generally seen or heard by rural minority individuals. Snowball sampling was also used to maximize recruitment opportunities. The training was described as an opportunity for participants to learn more about cancer diagnosis and treatment and to inform development of a future cancer support intervention. Trainees received \$100 for their time and participation. Institutional review board approval was received from The Johns Hopkins University. Written informed consent was obtained from participants.

Development of the Training Program

Guided by the PROCEED Model,⁴² oncology nurse researchers and CHW super-trainers collaborated to develop and refine a series of online and in-class training modules. The PROCEED model emphasizes a comprehensive approach that includes sensitivity to psychosocial barriers, saliency for participants, and evaluation; it also offers a framework for identifying educational intervention strategies. The model begins with desired outcomes and directs research backward to identify strategies for achieving particular objectives, including assessments of educational needs and/environmental factors related to health.⁴³ The training was informed by focus group participants from our prior community study, addressing survivorship needs and implementation of a cancer navigation project in rural communities.^{15,35} The training schedule was adapted from an existing CMS navigation project offered in East Baltimore, a program very familiar to the super-trainers. The CMS training plan was originally informed by the ACS patient navigator training and was further adapted by the study team, including the super-trainers.

Phase One Training

CHW participants completed a 3-day training to prepare them for roles as members of the research team who would provide direct navigation support to AA seniors and their support persons. The first 2 days involved self-directed learning via online modules, including knowledge about the research process and responsibilities of the research team. Day 1 modules also explored HIPAA, informed consent, cultural competency, and basic Medicare knowledge. Day 2 went deeper into the concept of CPN, including tools and educational resources, as well as information on cancer treatment education, motivating behavior change, and communicating with healthcare professionals. Day 3 utilized distance education led by registered nurses, CHW super-trainers and the principal investigators. Content was presented by CHWs and nurses through a series of interactive case studies with focused discussions, lectures, and multimedia presentations. Facilitators in Baltimore communicated via video-link with rural participants who had gathered at a central location in Virginia. Quizzes and informal discussion were used to assess CHWs' comprehension of the content, and to address trainee questions. The need for further training and an evaluation of the effectiveness of the TTT was assessed using pre- and posttests for online modules, a written evaluation of the overall training including Likert-type scales assessing overall satisfaction and comfort levels, and an hour-long focus group with the CHW participants.

The focus group transcript of the trainee class debriefing and responses to open-ended questions on evaluation forms were analyzed by hand by two team members with prior experience conducting qualitative analyses, using a qualitative descriptive approach⁴⁴ to elucidate CHW-participants' perspectives on the overall training, helpful aspects of the program, and potential obstacles when navigating rural seniors. These findings were compared with preand posttests and satisfaction surveys.

CHW trainees' feedback on this Phase One training will be applied going forward with community support persons, who represent the next tier of training (Phase Two). In this phase, the original CHW trainees will become the new super-trainers, and support persons will learn how to provide navigation assistance to a friend or family member with cancer.

Results

The Phase One CHW trainee class consisted of five AA CHWs who ranged in age from 49 to 60 years. The one male and four female participants were all long-term residents of their communities in rural central Virginia. Among the four trainees who reported their incomes, three lived with an annual income of less than \$35,000. Two trainees reported completing a

high school education or obtaining a GED, two had some college or an associate's degree, and one had earned a bachelor's degree. All trainees reported either a history of cancer in their families or a close personal relationship with someone who had cancer.

Overall, the trainee participants responded enthusiastically to the TTT, as reflected in unanimously high satisfaction scores (5 out of 5) on the post-training evaluation Likert-type scales and statements during the focus group such as, “[the training was] exciting,” “formative,” and “a lot of good information.” Trainees reported moderate to high levels of confidence in their abilities to follow a patient navigation protocol and their preparation to navigate seniors with cancer in their communities. Two trainees self-rated their confidence as 3 out of 5, and three rated their confidence 5 out of 5. Four trainees reported a high level of preparation to navigate an elder with cancer (4 or 5 out of 5) and the remaining trainee self-rated preparation as 3. Trainees were slightly less confident about their ability to document outcomes using study software (two reported preparation as 3 out of 5, two reported 4 out of 5, and one reported 5 out of 5). Overall scores on knowledge evaluation posttests for the individual training modules were high; however, comparison of posttest with pretest scores for each of the training modules to assess changes in levels of knowledge was limited by missing data related to delivery of pretests in an online format. Analysis of the transcript of the focus group held immediately after the completion of the in-class training day resulted in six general categories of trainee perspectives: (1) Needs of rural minority seniors with cancer, (2) the role of CHWs, (3) important qualities of CHWs, (4) helpful aspects of the training program, (5) potential obstacles to effective delivery of the intervention, and (6) potential resources. These perspectives are summarized in Table 1. In addition to the types of support that could be provided by a CHW, participants felt that other cancer survivors within the community could also serve as valuable resources, due to their experiences.

A debriefing of the entire study team resulted in multiple observations and lessons learned for future training sessions. These lessons are outlined in Table 2. One of the issues that emerged from this discussion was a recognition of challenges related to computer-mediated aspects of the training, such as the requirement for CHW participants to access and view self-study modules online before the in-class training day. It was clear from interactions with trainees before the in-class training day that levels of computer literacy varied widely within the group, prompting some study staff to question whether a baseline assessment of computer literacy should be added to future recruitment materials. A second issue that emerged was the scarcity of broadband Internet connections in some rural communities where trainees resided, adding to the challenges of utilizing online content. Finally, study staff felt that lower ratings of trainee confidence using the study software demonstrated during the documentation module might also have been related to the relatively high level of technical detail shared during that module and lack of a time for trainees to practice the skills required on actual computers. Overall, study staff perceived that minor modifications to the TTT designed to overcome individual trainee challenges related to technology, such as making initial training materials available in paper form, would facilitate greater levels of trainee preparation and comfort before the in-class training day.

In their responses to open-ended questions regarding what they liked most and what they liked least about the training, participants agreed that they welcomed the opportunity to participate in research that addressed a high priority need for AAs with cancer. Trainees also liked having greater access to information on cancer and cancer resources and the support of the study team to back them up in the field in their role as a CHW throughout the course of the study. Regarding the training itself, some trainees stated that they liked the web-based training modules, the availability of the study team to address computer-related issues, and the ability to connect with trainers in Baltimore remotely through the video-link technology.

Trainees also noted and appreciated the openness and respect for CHW trainees displayed by study team members. Among the aspects of the TTT that trainees liked the least was the inability, on the part of some participants, to access online materials before the in-class training day owing to “computer issues.” One trainee noted that interacting with study staff via intercom and video-link during the in-class training day was unusual and therefore less comfortable for her than face-to-face interaction. Several trainees expressed a desire to have had more time for discussion following the completion of the in-class training modules.

Lessons Learned

The research team benefited greatly from information gathered during prior focus groups with rural AA cancer survivors and incorporation of experienced CHW super-trainers in the development and implementation of the TTT. CHW super-trainers observed that inclusion in the planning process forced them to critically evaluate their past experiences conducting similar trainings. Furthermore, input from the CHW trainees, three of whom were later hired as study staff and research team members, also enhanced evaluation and revision of the TTT and planning of the next stages of research.

The distance learning format adopted for this TTT was considered convenient, cost effective, and less labor intensive for both the interventionists and the CHW trainees. Overall, trainees preferred distance learning to a traditional face-to-face format that might have required extensive travel for all involved. However, despite initially choosing a distance format over reimbursed travel to a central location for training, the frequency of technology issues, including some trainees’ inability to access and complete online materials and knowledge pretests related to lack of familiarity with online learning, indicates the need for additional assessment of trainee computer literacy and Internet access at the outset of the program. With this information, trainers could have devised a more structured program of individualized computer support. CHW trainers and trainees also suggested that mailed paper versions of pretests and screening tools would have facilitated a more thorough initial assessment of trainees by removing these barriers until they could be addressed on an individual basis. Further, information technology support at both the Baltimore and rural classroom sites was essential to troubleshoot minor issues as they came up throughout the video-conferencing portion of the TTT. One unexpected benefit of the TTT was that some trainees reported acquiring new or enhanced computer skills through their participation. At least one CHW trainee opened an email account for the first time. These suggestions will be incorporated into planning for Phase Two of the training program.

Constant communication among all members of the study team and trainee participants has been an essential component of ongoing evaluation and revision of this pilot TTT. This communication was enhanced by the posttraining focus group and study team de-briefings, regular email contact, as well as biweekly conference calls including the three CHW trainees who were subsequently hired as study staff. Phone contact has been found to be among the most reliable forms of communication with CHWs. Input from CHW trainees, super-trainers, and other members of the study team has been sought at every stage of the planning process for the next stage of the intervention and manuscript development. CHW trainees have also continued to demonstrate their value as key members of the research team by spreading information regarding the study within their local communities and fostering community partnerships. One trainee went on to organize and produce a televised segment about the study that has been aired repeatedly by a local television station. This CHW now provides cancer navigation support to local AA seniors and their support persons on a weekly basis. Two other trainees hired to the study have made visits to rural medical centers and other community organizations to educate community members about the study and the potential for greater involvement in future stages.

We believe our findings can be helpful to researchers and providers at all levels who are pursuing the use of CHWs to address systematic screening and interventions for patients receiving cancer treatment and that the training plan developed through this study has sufficient breadth and flexibility to be offered to audiences beyond our rural CHW community. Heretofore, a full description of the quality or content of CHW training to provide services to an AA senior population has not been provided. Clearly, the training and evaluation of CHWs is a critical factor in the success of such interventions, and their input regarding how to connect cancer patients with relevant and necessary support resources, particularly those that are most appropriate within the local community, should be continuous. As we have learned, training should be accessible and flexible, thereby providing trainees with resources to work within communities and to enrich their educational experiences. Findings from this work have been combined with findings from related studies^{14,45,46} to inform a culturally tailored support intervention to address resource, education, and support needs for older rural AAs undergoing cancer treatment.

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Table 1

Community Health Worker Trainee Perspectives.

Trainee Perspectives	Summary of Responses	Exemplar Quotes
Overall Training	<ul style="list-style-type: none"> • Learned a lot • More aware of seniors' needs • An exciting opportunity • Bridges gap 	<ul style="list-style-type: none"> • "an eye-opener" • "a lot of good information"
Rural & Minority Seniors with Cancer	<ul style="list-style-type: none"> •Lack appropriate support • Have no one to talk to • Don't get questions answered • Mistrust outsiders • Isolated from resources • Come from a "different generation" 	<ul style="list-style-type: none"> • "They do not have the support or... people that they can talk to or feel like they can confide in and say, "This is what's going on, where can I get help?"
Their Role(s) as Community Health Workers	<ul style="list-style-type: none"> • Break down barriers • Assess seniors' needs • Encourage asking questions • Teach strategies to be proactive • Educate seniors about changes in cancer care & resources • Dispel cancer myths • Assist in coordination of care 	<ul style="list-style-type: none"> • "We've got to teach people to be proactive in their care" • "information is spread all over everywhere and it's nothing together... you can steer them so that everything would be together"
Important Qualities of Community Health Workers	<ul style="list-style-type: none"> •Honesty • Active Listening • Relaxed Approach 	<ul style="list-style-type: none"> • "You've got to be up front and say, 'We don't know all the answers'"
Helpful Aspects of the Program	<ul style="list-style-type: none"> • Professionals available to answer questions • Can call research team anytime • Seniors and CHWs come from same communities 	<ul style="list-style-type: none"> • "the team and the doctors, that's a plus knowing that you're not just out there in the community by yourself"
Potential Obstacles	<ul style="list-style-type: none"> • Gaining self-confidence • Gaining seniors' trust • Resource availability • Local myths about cancer 	<ul style="list-style-type: none"> • "the resources, they don't cross county lines"
Potential Resources	<ul style="list-style-type: none"> • Local cancer society • Local cancer survivors • Vendors at health fair 	<ul style="list-style-type: none"> • "...long time survivors... they have probably gone through everything"

Table 2

Lessons Learned

Topic	Lessons Learned
Research Team	<ul style="list-style-type: none"> • Benefits of involving experienced CHW “super-trainers” in design & implementation of training; forced them to reassess their own activities/prior lessons learned • Benefits of incorporating CHW trainees into research team as study staff • TTT offered opportunity to engage local community in larger study; all CHWs trained will become resources for recruitment of study participants; 3 CHWs hired as study staff
TTT Format	<ul style="list-style-type: none"> • Cost-effectiveness, convenience & utility of distance-learning • Visual connection to trainers provided by video-conferencing enhanced learning experience during in-class portion of TTT • Some CHW trainees needed additional one-on-one training & computer support prior to participating in online education • CHW trainees might benefit from participating in research ethics training as a group during the classroom portion of the TTT (as opposed to completing it individually online) • Utility of offering learning materials in multiple formats (printed as well as online)
Information Technology (IT) Support & Technical Assistance	<ul style="list-style-type: none"> • On-call IT support was essential during distance learning & conference calls at all study sites involved • Some CHW trainees did not complete online portions of the TTT related to “computer issues”
Learning Assessment	<ul style="list-style-type: none"> • Importance of assessing CHW trainee's knowledge & comfort with online learning and access to internet at time of enrollment • Completion of online modules & associated pre-tests should be condition of participation in final in-class portion of TTT, so instructors can tailor content to learning needs of participants • Pre-tests & screening tools should be offered in printed format (to allow all CHW trainees to complete them regardless of initial comfort level with online learning tools)
Acceptability of TTT	<ul style="list-style-type: none"> • Enthusiasm & high satisfaction levels of CHW trainees • Distance learning via video-conferencing & completion of online modules preferred by trainees over all in-class format • CHW trainees were willing to overcome personal challenges with online technology to participate
Communication	<ul style="list-style-type: none"> • Constant on-going communication among all members of the research team and CHW trainees before, during & following TTT was key to improving the overall process