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An Evaluation of a Community-Academic-Clinical Partnership to Reduce Prostate Cancer Disparities in the South

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Abstract

Background—Engaging partners in the planning, implementation, and evaluation of cancer education programs is critical for improving the health of our communities. A two-year pilot

education intervention on prostate cancer decision making and participation in medical research was funded by the National Cancer Institute. The partnership involving community members and clinical staff at a cancer center was used to develop recruitment strategies and plan for the implementation of the intervention with African-American (AA) middle-age and older men and female family members. We assessed partners' perceptions of this community-academic-clinical research collaboration.

Methods—In year 2, eight project advisory council members were selected among existing partners and year 1 participants to serve as a formal committee. Council members were required to participate in telephone and in-person meetings and actively support recruitment/implementation efforts. At the conclusion of the project, 20 individuals (all clinical and community partners, including the eight advisory council members) were invited to complete a survey to assess their perceived impact of the collaboration on the community and provide suggestions for future collaborations.

Results—Most partners agreed that their organization benefitted from the collaboration and that various aspects of the advisory council process (e.g., both formal and informal communication) worked well. The most noted accomplishment of the partnership related to leveraging the collaboration to make men more knowledgeable about prostate cancer decision making. Suggested improvements for future collaborations included distributing more frequent updates regarding project successes.

Conclusions—Evaluating partners' perceptions of this collaboration provided important recommendations for future planning, implementation, and evaluation of community-based cancer education programs.

Keywords

prostate cancer; research collaboration; community and clinical partnerships; assessment

INTRODUCTION

Engaging partners and stakeholders in the planning, implementing, and evaluation of health and cancer education programs is critical for improving the health of our communities and encouraging community engagement, empowerment, and capacity building [1–10]. Prior to the second wave of recruitment for year two of a National Cancer Institute-funded pilot education intervention for African-American (AA) older men, AA middle-age men, and AA female family members about prostate cancer decision making and medical research participation [3, 6, 11, 12], a formal process was used to select individuals willing to serve on the project's advisory council.

While an advisory panel guided the first year's education program, the need for a more formal council and advisory process was recognized in order to engage people and groups in concrete activities over the entire project period [3]. Council members were recruited through word-of-mouth among existing project partners and year 1 participants. One-page application forms were developed and interested individuals were asked to mail or email their forms to the project lead and two coordinators who reviewed applications and contacted people to inform them they had been selected to serve on the council. Questions on the application included: "Why are you interested in joining the Advisory Council?" and "What skills and expertise will you bring to the Advisory Council?" This process has been used previously [1].

Eight individuals applied to serve on the council and all were offered positions. The council was comprised of four participants from year 1 of the study (i.e., AA men and women), a

nurse navigator from the cancer center partnering on the project (i.e., clinical partner), and three members of UsTOO, a non-profit cancer education organization (i.e., community partner). In addition to participating in one two-hour planning meeting and three one-hour telephone meetings during year 2 of the pilot program organized by the project coordinators, all council members were asked to assist with recruitment efforts by distributing a specific number of flyers throughout the community, contacting potential participants by telephone, and making in-person announcements at churches, barbershops, and community-related events such as health fairs. They were also tasked with helping plan activities such as determining the appropriate number of education sessions. All members were also present to assist with logistics and/or education content at each of the sessions. Specific Aims of the education program, developed collaboratively by the research team and partners, were to assess among AAs, (1) current knowledge and attitudes regarding PrCA prevention and screening and participation in PrCA research, (2) changes in knowledge and attitudes about research participation following a pilot education program, and (3) culturally appropriate strategies for promoting cancer research among AA communities. Findings from the community-based education program are reported elsewhere [3, 6, 11, 12].

METHODS

Advisory Council Assessment

At the conclusion of study activities in the second year of the project, all eight advisory council members were invited to participate in a 30-minute telephone survey to assess members' perceptions and opinions about the overall effectiveness of the council, their experience serving on the council, and whether any aspects of the council could have been improved. The assessment tool contained 7 qualitative and 8 quantitative questions adapted from other research with stakeholder advisory councils [1, 2]. Qualitative questions included: "How comfortable were you expressing your ideas and opinions?"; "What new information or skills did you learn or gain while serving on the community advisory council?"; and "What suggestions do you have for future advisory councils?" Examples of quantitative items with Likert-type response options ranging from "strongly agree" to "strongly disagree" included, "The purpose of the council was clearly stated"; "In person meetings were managed effectively"; and "Decisions were made as a group."

Seven of the eight council members agreed to participate in the evaluation; one council member could not be reached. All telephone interviews were audio recorded to ensure important information provided by participants would not be missed. Frequencies and percentages of the quantitative items were calculated. Qualitative responses were transcribed and examined for common themes [13].

Overall Partnership Assessment

A more comprehensive partnership assessment survey also was developed and emailed to all project partners – community partners (three chapter leaders of the UsTOO International Prostate Cancer Education & Support Network, year 1 program participants, and other advisory council members), clinical partners (National Cancer Institute Community Cancer Centers Program (NCCCP) cancer center directors, staff, and nurse navigators), and the academic (university-based) research team members. Twenty individuals from this community-academic-clinical team who were involved in the planning, implementation, and evaluation of the study were contacted to assess their perceived impact of the collaboration on the community, ideas for how the current partnership could be sustained, and areas where they thought the partnership could be improved for future education programs. Qualtrics™, an online survey management tool, was used to administer the survey. The survey, containing 35 quantitative items and eight qualitative questions, was based on three existing

instruments: Wilder Foundation Collaboration Factors Inventory [14], PARTNERTool [15], and Bell-Elkins' Principles of Partnership in a Community-Campus Partnership [16]. The 35 quantitative items focused on 18 aspects of partnerships including,

- History of collaborations in the community (1 item)
- Legitimacy of the collaborative group (1 item)
- Political and social climate (1 item)
- Mutual respect, understanding, and trust (4 items)
- Composition of the collaborative (1 item)
- Organizational benefits of the collaborative (1 item)
- Willingness to compromise (1 item)
- Sharing stake in process and outcome (7 items)
- Multiple layers of participation and decision making (1 item)
- Flexibility in decision making (1 item)
- Development of roles and policies (2 items)
- Adaptability (1 item)
- Pace of project development (1 item)
- Formal and informal communication (5 items)
- Goals, objectives, and priorities (4 items)
- Vision (1 item)
- Purpose (1 item)
- Leadership skills (1 item)

Response options for the 35 quantitative items ranged from “Strongly Disagree” to “Strongly Agree.” Eight qualitative, open-ended items also were included to give partners an opportunity to describe the collaboration in more detail. Questions included: “Please describe your organization’s single most important contribution to this collaboration”; “What aspects of this collaboration contributed to its success?”; and “What aspects of the collaboration could be improved?” Eighteen individuals (90%) completed the online survey – one person could not be reached and the second person chose not to complete the survey because she/he was not involved directly with the planning of the program. Frequencies and percentages of quantitative items were calculated using Qualtrics™. The survey tool organized participants’ qualitative responses into a chart. Project coordinators at the academic site used the chart to identify emergent themes [11].

RESULTS

Advisory Council Assessment Results

Quantitative Results—Most participants (n=6 or 85.7%) agreed or strongly agreed that the purpose of the council was clearly stated upfront. All participants (n=7 or 100%) agreed or strongly agreed that both telephone and in-person meetings were managed effectively, meeting objectives were always met, and participation of the council at meetings was encouraged. Everyone agreed that the group took into consideration the perspectives of others. Finally, all participants agreed that the council worked well together and project-related decisions were made as a group.

Qualitative Results—Overall, the council members shared positive experiences. When asked, “What do you feel worked well?” council members provided specific examples related to communication, how input was gathered from council members, study recruitment, learning new information, and finding out about the intended community members’ needs. Council members were quoted as saying, “Our communication with each other [worked well] for trying to recruit,” “The gleaning of the information and finding out about the community and their needs,” and “The communication was great.” Council members were comfortable expressing what they felt went well, but they found it difficult to discuss areas needing improvement. Most were quoted as saying that there were no areas for improvement. Specifically, one council member said, “Not sure what we could do to improve, maybe more communication with each other, but I don’t know how we can possibly do any more than we already did.” Another council member said, “I have no problem with it.” Council members also provide suggestions for improving the community-based prostate cancer education sessions. For example one council member said, “My only gripe would be the [eligibility] limitations that you put on for older male and younger male, it gets to a point where you just need people who are willing to participate and have a vested interest in, ya know, the project itself.”

All participants expressed that they were comfortable expressing their ideas and opinions with other members of the group. Council members reported things like, “Never at any time that I felt uncomfortable”, “I was very comfortable”, and “No problem expressing my ideas or opinions, I have some opinions and I am more concerned with getting the information out by any means necessary.” Additional members expressed that they felt the environment of the council was safe. For example, one council member said, “I was able to express my thoughts in a positive environment, I didn’t feel like I was walking on egg shells, just lots of support.”

Many of the council members reported that they felt like their ideas and opinions were taken into consideration during the planning of the education program, but most of the council members were unable to provide concrete examples of when they saw their idea or opinion expressed during the program. Council members reported, “Absolutely, I can tell when I shared my ideas, there were positive responses” and “Yes, but I can’t remember anything specific.” One council member said the tribute ceremony at the final event for participants who passed away over the year was very special to her and she was happy that it was carried out, “. . . just doing our celebration of life ceremony, that meant a lot to me, we worked to do that at the end.” Although all but one of the council members were unable to provide specific examples of how their ideas or opinions were being implemented, they expressed that this was a collaborative process.

While the council contributed greatly to the organization of the education program, which was a main task, we also wanted to know if they gained new information and skills as a result as serving on the council. Some of the council members reported learning new information and gaining listening and collaboration skills as a result of their service. One council member said he learned a lot personally, “Probably, my listening skills were made to be a little better, and to just listen to other people, better listening skills.” Another participant learned more about prostate cancer. An additional participant said that she learned to work with others, “Surround yourself with [names omitted here] for any project you are gonna work on.” Council members found it hard to offer areas of improvement and also did not have very many suggestions for future project advisory councils. Two council members provided recommendations regarding recruitment and eligibility. “Nothing specific [to recommend], but just to get more participation from the community once we start” and “Get started earlier, relax restrictions, get more men.” One member in particular really wanted the program to be larger and he wanted to reach, “A minimum of 100 [men].”

At the end of some of the interviews, council members wanted to offer additional information. Most members expressed their gratitude to the prostate cancer pilot project team for the work they are doing to improve the health and cancer knowledge of the community. Representative comments included, “I appreciate everything you guys have done, and do;” “It was a good experience for me, I thought it was a worthwhile experience;” and “I feel honored to be apart, and regret not doing more. I hope that I can do this again, give it a full 100%, I would encourage anyone to do it.”

Overall Partnership Assessment Results

Quantitative Results—Most participants (n=17 or 94.4%) agreed or strongly agreed that the political and social environment was right for starting a prostate cancer program. The majority (n=11 or 61.1%) also agreed or strongly agreed that similar collaborations had previously taken place in the community. Most partners agreed or strongly agreed that the collaborative had mutual goals and objectives (n=17–18 or 94.4%–100%), a shared vision for the project (n=18 or 100%), clear policy and guidelines (n=18 or 100%), and a strong belief that it would be difficult for any one organization to accomplish these goals outside of the collaborative (n=17 or 94%). In addition, almost all partners felt that their organization benefited from the partnership (n=18 or 100%) and the collaborative was comprised of the appropriate partners to accomplish the target goals (n=17 or 94%).

All partners strongly agreed or agreed that they had a mutual trust and respect for one another and demonstrated this respect through gestures such as extending courtesy to everyone in meetings or consider seriously any issues raised by a partnering organization or member. Most members also agreed or strongly agreed that they (1) had open lines of communication through formal (e.g., meetings) and informal links (e.g., telephone call) (n=17 or 94%), (2) were open to compromising on important aspects of the project (n=18 or 100%), (3) were open to discussing different options before final decisions were made (n=15 or 83.3%), and (4) felt that there was always adequate time for members to take information back to their organizations to confer with colleagues prior to making an important decision (n=16 or 88.9%). Most (n=16–18 or 88.9%– 100%) partners agreed or strongly agreed that all members shared a stake in the process and outcome of the collaborative including their commitment of time and resources to reach targeted goals and sharing credit for any successes. In addition, most partners were confident that members of the collaborative were able to support the efforts necessary to coordinate activities related to the project (n=17 or 94%), but also were able to adapt to changing conditions, such as less funding or budget cuts (n=16 or 88.9%). Furthermore, all partners agreed or strongly agreed that those individuals in leadership positions (i.e., PI and project leader at academic site) had good skills for working with other people and organizations.

Qualitative Results—When asked about their organizations’ single most important collaboration for the project, partners primarily commented on their active involvement in recruiting participants and their contributions to the planning, organization, and implementation of the prostate cancer education sessions. For example, one partner listed his/her organizations’ most important contribution as “the resources needed to allow project to move forward (e.g., meeting space, manpower needed to assist with the multiple hours of active recruitment by staff).” There were three main aspects that were commonly reported as contributors to the success of the partnership: (1) the partner’s commitment to the community, (2) the partner’s dedication to accomplishing targeted goals, and (3) the excellent communication between the partners. The most common “greatest accomplishment” reported related to making the men in the community more knowledgeable about prostate cancer and prostate cancer screening, but also emphasized the critical importance of the academic/clinical/community partnership in achieving this

accomplishment. For example, one partner wrote, “educating AAs in our community about clinical trials and prostate cancer, encouraging those people to share the information with friends and family. I feel we have touched 100s of people in our community....”

Aspects of the collaboration that partners thought could be improved included (1) meeting more often and receiving regular written updates about the project accomplishments/successes, (2) involving more individuals/volunteers in the recruitment and implementation process, and (3) reducing the time commitment of participants by shortening the length of education sessions or the number of times they must attend sessions, and (4) securing additional funds so that participant incentives could be increased and in order to support future research. Most partners felt that the pace of the program’s development and implementation was appropriate, although a couple of partners felt that too much time elapsed between the time of participant consent and the time at which a person completed the entire education program.

Everyone agreed that their ideas and opinions had been taken into consideration as a part of the shared vision of the collaborative. For example, one partner stated, “Several of my suggestions were incorporated into our [recruitment] plan such as using AA barber shops for recruitment.” There were multiple ideas provided for possible next steps for the collaboration. These ideas included continuing the collaboration to provide education to the community and engage in additional disparities focused cancer research projects, expanding the collaborative to include additional partners, involving more staff to support project implementation and evaluation efforts, identifying ways to make the current education program accessible to more community members, and expanding the topic areas to include additional cancers (e.g., breast, colon, lung). When asked if there were any additional things they would like to share, many partners simply expressed their gratitude for being a part of the project and felt that it was a rewarding experience. For example, one partner stated “This collaboration was one of the most successful that I have participated in... during this collaboration there was always a win-win environment.”

CONCLUSIONS

There were limitations with the advisory council and overall partnership assessments. One member of the council could not be reached for the council assessment and two members of the overall partnership team did not complete the partnership assessment. Therefore, their perspectives (which may have differed from the remainder of the group) were not considered in the outcome of these assessments. In addition, because of the nature of the partnership (i.e., partners had a history of collaboration prior to the partnership assessment and all organizations have a stake in the success of the project), there may have been some bias in people’s responses. Furthermore, these results are not intended to be generalizable to other settings or community education interventions. Despite these limitations, the study utilized a strong mixed methods design and provided valuable information that can contribute to the development and sustainability of partnerships to eliminate cancer-related health disparities through the planning and implementation of innovative and collaborative programs. Sustainability of this community-academic- clinical partnership is evidenced through additional community education forums, planning of additional education programs, and collaborations on grant submissions to continue work on prostate cancer decision making statewide.

Involving clinical and community partners in the planning and implementation of a prostate cancer program was critical for the planning of this project because it elucidated key perspectives that may not have otherwise been considered. In addition, clinical and community partners had historical knowledge about and existing relationships with the

target community which was extremely beneficial for program recruitment and establishing rapport with community members [3]. Finally, selecting and establishing a formal project advisory council was advantageous because it provided an opportunity for representatives from partnering organizations to convene regularly and provide perspectives on behalf their group or agency.

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