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A Small Grants Program to Involve Communities in Research

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Abstract

A key tenet of community-based participatory research is that communities be involved in all facets of research, from defining the problem to identifying solutions, to assisting in the research, and to participating in the publication of results. In this study, we instituted a small grants program for community participation. A Request for Applications (RFA) was developed and circulated widely throughout the Valley. The RFA sought proposals to address health disparities in cancer education, prevention, and treatment among Hispanics living in the Valley. Funds available were \$2,500.00–3,500.00 for 1 year's worth of work. To help evaluate the progress of the RFA community projects according to the perspectives of the Community Advisory Board (CAB), an open-ended, semi-structured interview was created and administered by a former staff member to CAB members. In 4 years, ten small grants proposed by community members were funded. Funds allocated totaled approximately \$25,000. Interviews with CAB members indicated that the RFA program was perceived positively, but there were concerns about sustainability. Our community grants program resulted in the implementation of several novel cancer prevention programs conducted by a variety of community organizations in the Lower Yakima Valley.

Keywords

Community based participatory research; Community grants; Cancer education; Community advisory board

Introduction

A key tenet of community-based participatory research (CBPR) is that communities be involved in all facets of research, from defining the problem [1] to identifying solutions [1,2], to assisting in the research [2,3], and to participating in the publication of results [2,4,5]. Too often, the reality is that the researchers are heavily involved in the research component and the community member roles are limited to those of facilitators, implementers, and assistants to the researchers. For community members to gain practice and expertise in research, however, it is important that they have vital roles in the research component. Through involvement in all aspects of the research enterprise, the community members can gain the experience they need to pursue quality research on their own [4,6].

The Community Network Program (CNP) funded by the National Cancer Institute (NCI) is committed to a CBPR approach in educating communities about cancer [7]. Targeting communities suffering from cancer health disparities, the 25 CNPs nationally strive to use a CBPR approach to help reduce the cancer health disparities among American Indians,

Hispanics, African Americans, Asian Americans, and Pacific Islanders [7]. An underlying principle of the involvement of communities is that communities have the power and ability to reach their members; further, communities have the experience to conduct research activities that will reach the underserved. As the CNPs have developed, many have undertaken novel ways to involve their communities in research.

One way to involve communities in research is through the allocation of direct funds to community groups and organizations. Providing direct funds enables the groups and organizations to conduct their own research. This provides experience and learning. Adding technical assistance to community groups is a way to increase the learning opportunity. Further, such actions are empowering to community agencies and may lead to other grant proposals and research activities.

In this paper we report on one CNP and its effort to involve communities in research. Using a “small grants” approach, the CNP funded ten community research programs in the past 4 years. We report on the community research endeavors, the outcomes, and the community response to the small grants.

Methods

Setting

The Hispanic Community Network to Reduce Health Disparities is a CNP located in the Lower Yakima Valley of Washington State. The Valley is a rural agricultural area, where much of the economy is related to agriculture. The work is largely carried out by Hispanics who comprise about 60 percent of the Valley’s population. The Hispanic population began migrating to the Valley shortly after World War II and many have continued to migrate to the Valley in recent years. A number of the migrants have settled out and continue to work in agriculture and related activities (e.g., in packing warehouses).

The Hispanic population in the Valley is underserved in a number of ways. They have low educational rates (more than 50% have less than an 8th grade education), are economically depressed (48% fall under 200% poverty level), and are largely uninsured (over 40% have no regular insurance plan) [8-10]. Spanish is the only or the preferred language for many Hispanics in the Valley. The Valley has a network of community health clinics that provide low cost medical care to the population [11]. Clinics are focused on primary care and do little in the way of cancer prevention or cancer screening.

Community Advisory Board

The CNP has a Community Advisory Board (CAB) consisting of 20 members. This CAB has been involved in the CNP project since its inception. One of the activities the Board desired to pursue was the giving of small grants to community organizations and groups that wanted to pursue activities related to cancer prevention or treatment. Arguing that much was already going on in the Valley and that local groups and organizations have the capacity to conduct cancer education, the CAB proposed an annual request for proposals (RFA) that would contribute to achievement of the specific aims of the grant. Researchers and Board members worked together to develop a process of calling for and funding responses to the RFAs. In the process that developed, three principles emerged: Groups and organizations should have equal opportunity to apply; the CAB would be involved in selecting worthy projects; and each project would need an evaluation plan as was consistent with the CNP national strategy.

Request for Proposals (RFA)

An RFA was developed and circulated widely throughout the Valley. Essentially, the RFA stated that proposals were being sought to address health disparities in cancer education, prevention, and treatment among Hispanics living in the Valley. Funds available were \$2,500.00 to \$3,500.00 for 1 year's worth of work. The researchers, along with Valley staff, held a 4 hour Technical Assistance meeting to assist with the application process. A simple application was developed that included the following pieces: A statement of the proposed work; a statement of how the project contributed to the broader aims of the CNP; the qualifications of the proposer, an evaluation plan (which was often developed with the Evaluation Director of the CNP); what data would be gathered; what data would be turned over to the CNP, and a budget.

Selecting Projects for Funding

Three cycles of applications have occurred (2006, 2007, and 2008). (The grant expires in 2010 so no additional RFAs were requested after the summer of 2008. In each cycle, we convened a small subcommittee of the CAB (5 members) to meet with the researchers and Valley staff to review the proposals. Proposals were reviewed on the following criteria. Did the proposed work plan have scientific merit? Did the description of the project leader suggest the organization could do the work? What contribution would the project make to the overall CNP? How adequate was the evaluation plan? Was the budget suitable and reasonable?

Community Advisory Board and Community Project Evaluation Interview

To help evaluate the progress of the RFA community projects according to the perspectives of the CAB, an openended, semi-structured interview was created and administered by a former staff member to CAB members. CAB members and RFA project leaders were sent a letter requesting their participation in the interview; staff contacted members at a later time to set up a meeting date at the individual's convenience. Interviews were given a participant ID number in order to keep them confidential; all interviews were audio recorded for integrity and accuracy. Prior to starting the interview, participants were asked to sign a consent form for the interview, and a copy of the consent form was given to them for their records. With the completion of all voluntary interviews two intervention staff transcribed all interviews into separate word documents and coded each interview for major themes and ideas that were brought up by the participants. Once this process was completed everything was collected and put into one word document for further evaluation by intervention staff.

Results

During the 3 years, we received 12 proposals and funded 10 (Table 1). The projects are summarized below.

Small Grants Funded by the CNP

Cervical Cancer Outreach Program—This project was initiated by a community-based organization that provides services to women who are affected by domestic violence. The project aimed to assess changes in cervical cancer knowledge and Pap testing rates following the delivery of in-home education sessions to Hispanic women aged 18 and older. The intervention, delivered by organization staff trained by Fred Hutchinson Cancer Research Center (FHCRC) interventionists, addressed risk factors for cervical cancer, common barriers to Pap testing, and resources for obtaining needed screening. The evaluation consisted of a baseline survey of the organization's interventionists completed prior to the intervention and a follow-up survey completed 3-months after the intervention. A total of five staff were trained in the delivery of the intervention. The trained staff delivered interventions to 28 women; of

those, 18 completed both pre-test and post-test. Women were asked about change of knowledge and Pap testing behavior. Of the 27% of women who were out of compliance at baseline ($N = 5$), 100% received Pap tests after the intervention.

Student Cervical Health Program—This project was a three-way collaboration between the Fred Hutchinson Cancer Research Center, the Indian Health Service, and the local Department of Health. The project aimed to increase knowledge about Human Papillomavirus (HPV) among adolescent girls (grades 7 and 8). Yakima Valley high schools having a high proportion of Hispanic students were selected to participate in the project. The intervention was administered during a health class exclusively for girls and consisted of a 20-min slide presentation that discussed HPV, Pap test screening, and HPV prevention. Prior to the intervention, students signed a consent form and completed a self-administered baseline questionnaire. Immediately following the intervention, follow-up questionnaires were completed. The evaluation of 43 students examined pre- and post-test difference in knowledge and intention to receive a Pap test. There were significant increases in both knowledge ($P < 0.001$) and intention to be screened with a Pap test upon reaching age 21 ($P = 0.017$). Unfortunately, the Health Department had to pull out of the project, and the community person at the Indian Health Service left the area, so only one school received the intervention.

Prostate Cancer Radio Outreach Program—The impetus for this project arose from staff at a local Spanish-language radio station with an extensive history of producing and airing educational programs to meet the health needs of the Yakima Valley community. The program was initially funded in 2006 and we received subsequent proposals, which were funded, in 2007 and 2008 to repeat the radio broadcasts. Year 1 consisted of three components: (1) a focus group that enrolled Hispanic men aged 50–79 and assessed levels of knowledge about prostate cancer and key barriers to screening; (2) the production and airing of a 90-second broadcast that promoted prostate cancer prevention (the segment was aired 60 times throughout the funding period); and (3) a 1-hour live radio program that promoted prostate cancer health, education, and prevention. During the call-in program a local Spanish-speaking physician was interviewed, and listeners could call in and ask questions. The show was aired a number of times.

In the second year of funding, another live radio show was aired and a new 90-second broadcast was created; in addition, a number of 60-second informational capsules that promoted prostate cancer health were created. The informational capsules were aired 64 times throughout the funding period. Another addition to the intervention plan was the distribution of “healthy prostate” brochures at local community events such as health fairs.

In the third year of funding, the radio station asked for assistance in conducting another focus group of men aged 50 and older. The goal was to acquire specific information on men’s knowledge of, attitudes toward, and beliefs about prostate cancer. Based on the results, the radio station developed a 1 hour show to dispel myths and encourage men to talk to their physicians about prostate health. A local man, who had recently recovered from prostate cancer, spoke on the show about his experiences. The show was aired a number of times.

The evaluations for each of the three radio station projects were the number of broadcasts that were done and the number of brochures that were distributed. As seen above, the information capsules and public service announcements, as well as the information shows, were aired a number of times. Over 250 brochures on prostate cancer were distributed.

Smart Nutrition Choices

This project was a collaboration with a local private 4-year university, the faculty of which was interested in raising student knowledge about nutrition and increasing the number of

healthy food offerings in the cafeteria and vending machines on campus. With the guidance of the Nursing School program director, nursing students conducted baseline questionnaires among students purchasing food at the cafeteria. An intervention involving informational poster boards presentations was delivered in the school cafeteria, the library, and the classrooms. A follow-up survey was administered to the same students during the following spring semester. Observational data indicated that cafeterias and vending machines changed their offerings. Further, the student surveys indicated that students were eating more salads and less fried food on campus; however, the number of respondents was very small ($N = 16$).

“Mommy I’m Hungry”: Good Eating for Little Ones-in Progress

This project targets Hispanic female high school students (aged 15–18 years) who are pregnant and/or have children between the ages of 0–3 years. The goal of the project is to educate young mothers on healthy nutrition habits for their children and themselves; with the ultimate goal of instilling healthy lifetime eating habits and reducing the lifetime risk of cancer and other chronic diseases. A series of four education sessions are being held within a month, and each session lasts approximately 1 hour. The sessions address nutrition during pregnancy, breast feeding, introduction to solid foods, grocery shopping within your budget, and healthy options when eating out at restaurants. The effectiveness of the intervention will be evaluated using data from pre- and post-test, given at the beginning of the first session and at the end of the final session, respectively.

Women and Cancer: Improving Support in their OWN Communities

The goal of this project was to offer Spanish-language support groups to cancer survivors and care-givers of cancer survivors. The project met an important need in the community by providing free support groups in Spanish in areas that have limited or no access to these resources. The funded organization currently provides support groups to English-speaking cancer survivors and caregivers and offers facilitator training. Funding through this partnership provided the impetus to train a Spanish-speaking facilitator and to offer Spanish-language services. As an evaluation of the program, baseline and follow-up survey were to be administered to participants to assess cancer-related quality of life. In reality, the participants in the program changed from session to session, making it difficult to administer questionnaires, and ultimately, the community organization stopped the questionnaires.

Informative Sessions about the HPV Vaccine and HPV-Training in Progress

For this project, Hispanic parents who have daughters between the ages of 9–25 years and/or women who are 26 and under are targeted for an education program designed to increase knowledge of cervical cancer and HPV. The project aims to recruit healthy women from a community food bank. Two classes will be held; one in Spanish and one in English as determined by the needs of the participants. A pre- and post-test will be given to participants who are 18 years and older; administered immediately before and after the class. Questionnaires will evaluate changes in knowledge, and the intention of getting the vaccine for themselves or their daughter. Owing to extensive Institutional Review Board (IRB) delays, this project is only now occurring. Food bank staff are being trained in HPV and the HPV vaccine information.

Healthy Habits for Life-in progress

A local community hospital submitted a proposal for funding of this project, which is delivering a Healthy Habits for Life nutrition and fitness curriculum developed by the Washington State Dairy council. The project targets Hispanics who are 18 years and older and fluent in English (as the curriculum is only available in English). Participants take part in a six-week curriculum that covers topics such as healthy eating, fitness, grocery shopping, eating on the run, and

maintaining lifelong habits. A pre-and post-test is given to the participants at the start of the first session and immediately after the final class session. To further evaluate the effectiveness of the program, a focus group will be conducted with the participants to solicit feedback on the curriculum and format of the classes.

Community Advisory Board Reactions to the Small Grants Process

A total of 17 of the 20 CAB members agreed to participate in a qualitative semi-structured interview. Each interview lasted about 30–45 min. Interviews were transcribed and coded by two research staff, and major themes and ideas were identified.

Major Themes in Community Advisory Board Members

One of the major themes was the novelty of the community RFA process. Participants felt that it was a “great” or “good” idea. One participant stated, “It’s good, I think it gives us a lot, because we didn’t think about doing anything like that before you presented that idea to us. And it seems that it’s gonna be really something good for everyone [in the community]”. Another participant added that the RFA process allowed organizations to enhance services to the community, “I think they are a good idea, they do help a lot of folks that are trying to do activities around the community but they don’t have the funding. So, I’m, I’m thinking they’re good, they’re good”.

Another prominent theme was that the RFA proposals brought new opportunities for community organizations to obtain needed financial resources and for such groups to work together. One of the participants felt that this “opportunity” not only established financial security but also connections with other local organizations, “...I think it encourages organizations to work together and especially helps the smaller ones get in to help people and also receive some funding to do that, you know with smaller organizations it’s hard to allocate resources when there is none coming in.” Another participant felt that regardless of the size of the organization, the mini grants brought much needed financial support, “...It brings a resource that small groups or bigger groups in the Valley...sometimes need to carry out the activities...its an opportunity and a benefit”.

Participants believed that the RFA grants had varying levels of impact within the community. In one instance, a community organization representative recounted anecdotally how the program affected community members, “...it’s hard to evaluate but...a lot of people are learning more...and then they begin to understand the importance of the information that we air. Then they begin to take action on their part. I think...just from the comments that I get out in the community, they appreciate that, appreciate knowing more....” Another participant stated that the impact was in reaching people that would not otherwise be reached and creating programs that a single organization could not imagine, “We can’t do all the work in communities, there’s no way we could do all the work. And if we throw it out to other organizations they end up doing work that either we wouldn’t have thought of or that we can’t do.”

Sustainability was both a concern and an advantage of the community grants program. Several participants also expressed concerns about the sustainability of program efforts and fears that much needed programs would be implemented in the community only to see them leave at the end of the funding period. Once the grant was complete, some participants noted, nothing was there to continue what was started, “I think they do (have an impact)...And with most other places if they don’t have those little grants, they start them but then they end and that’s it. They don’t keep going, they don’t exist, you know that kind of a thing. So, it’s a good thing and a bad thing, because there’s good things that come out of it but they’re not sustainable.”

Challenges and barriers were discussed in various forms throughout the individual interviews. There was unfamiliarity with an application process, the difficulty of developing a budget and evaluation plan, language barriers, and education barriers. One participant had no problems with the initial application process but noted that some applicants encountered difficulties with the project requirements for evaluation and the funding amount. "I had no problems with the application process, not at all...but I know there are some organizations that have had some difficulty with it. And I think that just because it's new and they're not accustomed to being part of things like this. But, I think the other part to it that I heard often was that um, there was expectations for so much but there was such little funding." Another participant felt there were many forms of barriers that a potential applicant had to face especially if there was no prior experience with this field, "Language barriers, educational barriers, knowledge based barriers, there were all sorts of different considerations that you have to keep in mind. Obviously the language barrier is the biggest and prior to working in nonprofits, I wouldn't have had a clue how to write a grant or a proposal or anything like that...." For one participant this process was a new experience for her as she had never done anything along these lines in her work before, "...we've never done it before, we have put applications for grants before, but not for projects, so the wording and also the budget itself, I didn't, I didn't know just how to do it."

Participants felt very strongly about the level of assistance that was given or expected to be given during the application process and the program implementation phase. Individuals at times felt that too much assistance was given through some of the application phases. Others felt that there wasn't enough assistance and that more special sessions or tutorials should be created to enhance familiarity with the process. Other interviewees that felt there were adequate amounts of assistance from research staff whenever it was needed throughout the entire process. "There were instances when the interviewees felt there was an adequate amount of assistance whenever they needed it,"...with them [the research staff] it was whatever I needed...they were easy to get a hold of, and to talk to them, and they were really helpful...they even came to a couple of classes and participated to see what it was about." One participant commented on the need to expect more independence from funded community partnerships, "...I'm not sure how much you want to hold somebody's hand because taking that big of an interest in their project, they may feel as if you're going to help them with their project when it starts... But you need to give them the tools on how to do it." Others expressed the contrary view, suggesting that a special session was needed to help with the application process, "...a lot of people are afraid to do it [fill out an application]. Maybe what would be helpful is if we had one of our meetings, we actually went through and helped them out. Cause when you get home and then you go, 'I don't know what this means?' And you're afraid to put the wrong answer down, not sure what it is they are asking for, so maybe a little bit more guidance at, while you're doing them, so more of us will turn them in."

Discussion

Our Community Networks project undertook an innovative strategy for engaging community organizations in research, attempting both to generate opportunities for sustainability, and for trying to reach particularly underserved segments of the Hispanic population. Our Community Grants program offered a small amount of seed funding (\$2,500–3,500) for small cancer-related projects conducted by local community organizations. Throughout the project, ten community organizations were involved in the grants that totaled approximately \$25,000.

Several previous studies have included a community partner in their research [1-3,12,13], however, few, if any, have undertaken a community grants programs, where the ideas come directly from the community organization. In general, our Community Grants program was positively received by the community, with CAB members noting anecdotally that the grants

spawned the creation of unique programs and reached those who would otherwise not be reached by community-based intervention programs.

A concern expressed by some interviewees was that the programs were not sustainable; thus, any positive impact would only be achieved in the short-term. This concern has been expressed by other researchers who implement community-based programs [14,15]. This may reflect a view of sustainability that focuses on monetary resources. Israel et al. [4] and others note that true sustainability can be achieved through training, mentorship, and the sense of community ownership of a project, all of which were provided with our small grants process.

Some direct sustainability can be seen. For example, the school-based cervical cancer screening curriculum has been adopted by two schools as part of their standard health classes. The cancer support groups are continuing with survivor facilitators and, indeed, have expanded from one group to four groups, including a separate group exclusively for men. The radio station continues to work with the project to produce cancer-related messages and broadcasts. The local college changed its cafeteria food offerings to healthier options.

As researchers, there were several difficulties that were encountered as part of the RFA grant process. Requirements of our organizational Institutional Review Board (IRB) mandated that we provide more detail about projects than that provided in the RFA application. In some cases (e.g., the pregnant adolescents study), the demands of the IRB delayed the study for 18 months because of the focus on children. In all cases, the researchers had to construct a protocol for the funded projects so it could be reviewed by IRB. This process not only delayed the start of the projects, it also confused community members who were not familiar with IRBs. We found that as researchers, we had to do considerable education in IRB roles and IRB regulations.

Differences in expectations existed between our research team and the community organizations in the extent of evaluation that was required by the parent project. In some cases, community organizations were insistent on the use of a very brief questionnaire that did not measure any reasonable outcomes. In other cases, the community organization would agree to a specific evaluation, but would not administer a pre-test or sometimes, a post-test. The focus of the community organizations was to make a difference, not to document that difference. The CAB interviews, however, indicated that CAB members wished to know more about the outcomes of the individual projects; thus, more emphasis needs to be paid to the evaluation area.

Another downside of the community projects was that the research effort was often so small that the results were not publishable. This makes the projects much less desirable for researchers and funding agencies who need to demonstrate their success through published manuscripts. Although the process was instrumental in involving community members, and thus congruent with community based participatory research, the lack of robust results prevented community members from being involved in the publication process.

On the other hand, in some cases, the partnership with community organizations developed into a larger funded project. Our work with the local radio station in developing Spanish-language cancer prevention messages led to the submission of a subsequently funded proposal to develop *fotonovelas* and *radionovelas* to provide much sought-after information about the human papillomavirus (HPV). Similarly, our work in tobacco control led to a “Quit and Win” contest funded by the American Lung Association.

Despite the problems we encountered, the community grants program engaged community members in the research as an active participant rather than a passive observer. It fell within the principles of CBPR as expressed by Israel et al. [4] Further, it gave community members

ownership of not only the small individual projects, but also led to better understanding of the larger parent project.

Finally, the grants program also provided researchers time to assess the capacity of local organizations to conduct research in cancer. For example, the local hospital proved to be very interested in research and had both the infrastructure and the resources to become an active participant. This led to us working with them on another funded project in the Valley. Similarly, we found vast experience in the local Spanish-language radio station and are working more intensely with it. This kind of knowledge about the individual organizations is a factor that is important for future collaborative efforts in the Valley.

Conclusion

In conclusion, our community grants program resulted in the implementation of several novel cancer prevention programs conducted by a variety of community organizations in the Lower Yakima Valley. The programs inspired community ownership and were thought to result in the provision of services and programs to individuals who were not reached by standard health promotion programs. Nevertheless, the research rarely resulted in publishable research, and some community members expressed concerns about the sustainability of the programs. These advantages and disadvantage should be assessed by other groups considering such programs.

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Table 1

Characteristics of funded projects

Title	Population group targeted	Number of participants		How outcomes assessed
		Goal	Actual	
Cervical cancer outreach program (2006)	Hispanic women who are especially hard to reach	31	80	Pre- and post- surveys will evaluate knowledge of cervical cancer and prevention
Student cervical health program (2006)	Hispanic and non-Hispanic adolescent girls	1,000	43	Pre- and post- surveys will evaluate students' knowledge about HPV, Pap testing, and prevention
Prostate cancer radio outreach program: 1 (2006)	Men age 50 and over	12	5	Focus group post-broadcast of the outreach show ^a
Smart nutrition choices (2006)	Students and Faculty of Heritage University, age 18 and older	20	71	Pre- and post- education surveys
"Mommy I'm Hungry": good eating for little ones ^b (2007)	Females age 15–18, with children 0–3, and/or pregnant	50	Currently in process	Pre- and post- test to assess overall knowledge of basic nutritional issues
Women and Cancer: improving support in their own communities: 1 (2006)	Women 18 and over who have cancer or have a close friend or relative that has/had cancer	20	8	3-month and 6-month evaluation survey that will assess individuals' needs, quality of life, and changes in both
Prostate cancer radio outreach program: 2 (2007)	Men age 50 and over	12	12	Focus group post-broadcast of the outreach show
Prostate cancer radio outreach program: 3 (2008)	Men age 50 and over	12	9	Focus groups post-broadcast of the outreach show
Healthy habits for life ^b (2008)	Adults age 18 and over, who can read and write in the English language	50	Commenced 7/1/09	Pre- and post- surveys for trainers and class participants. Glucose and blood pressure tests will be administered to all participants in class
Informative Classes about Gardasil and HPV ^b (2008)	Hispanic mothers and their daughters, ages 9–25	50	Waiting for IRB Approval	Pre- and post- surveys will evaluate changes in knowledge and intention of parents to vaccinate their child and/or the intention of young women to receive the vaccine

^aIt was not possible to know how many men listened to the multiple radio messages and the radio outreach program that was provided

^bIndicates that project is in development phase