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Perspectives of Community Advisory Board Members in a Community-Academic Partnership

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Abstract

Background: Community-academic partnerships are increasingly used to engage community members and researchers in research activities; however, little is known, about the motivations and perceptions of community members to participate in such projects.

Objectives: The overall goal was to elicit Community Advisory Board (CAB) members' motivations and perceptions of involvement in the community-academic partnership.

Methods: An external evaluator conducted fifteen one-on-one semi-structured interviews with CAB members of NIH-funded projects. Coders conducted a conventional content analysis to derive themes from the interview data.

Results: Emergent themes were grouped into four categories: CAB members' 1) motivation to participate in the project, 2) perceptions that they had insider information, 3) views of roles and responsibilities in project planning and implementation, and 4) challenges and suggestions to improve the community-academic relationship.

Conclusions: This study found substantial evidence that CAB members perceived they were working to involve the Hispanic community in health promotion.

Keywords

Community-academic partnership; CAB members; roles & responsibilities of a CAB; challenges in a CAB; insider information

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Conflict of interest:

The authors declare that they have no conflict of interest.

INTRODUCTION

Community-academic partnerships are increasingly gaining traction as an equitable approach to engaging communities in health behavior change.^{1,2} For example, the National Cancer Institute's Community Networks Program Centers (CNPC) has established community partnerships at the local, regional, and national levels. The CNPCs have much experience in the development of community-academic projects.³ Similarly, the National Institute of Minority Health Disparities⁴ and the Centers for Disease Control and Prevention⁵ required investigators to develop such partnerships to address interventions around chronic diseases. These agencies use principles of community-based participatory research (CBPR) to integrate local knowledge into research endeavors.^{6,7}

Although the extant literature on community-academic partnerships focuses on the roles the researchers should take in working with the community,⁸⁻¹⁰ few studies examine the perspectives and experiences of community members who participate in the research process.^{11,12} There is a paucity of literature identifying the perceptions of community members who work in a community-academic partnership.

Community Advisory Boards (CABs) often form the structure for involving community members in a partnership, and can play an important role as collaborators and gatekeepers to the community.¹³ Understanding how CAB members perceive their roles is a way to grasp community perceptions of involvement in community-academic partnerships.¹⁴ Such information could help guide future projects that aim to establish similar partnerships to address chronic disease and promote public health.

In an effort to enhance the literature relative to community partner perceptions and experiences about participation in community-academic partnerships, we interviewed CAB members who guide cancer and diabetes projects being implemented in a community in Eastern Washington State. As the motivations, perceptions, and roles and responsibilities of a CAB in public health research projects—from the perspective of the CAB members themselves—is a relatively unexplored topic, a qualitative approach was appropriate to ascertain values and opinions of this population¹⁵.

METHODS

Study Setting

This study took place in the Lower Yakima Valley, which is a rural, agricultural region of Washington State, where 69% of the population is Hispanic/Latino, mostly of Mexican descent.¹⁶ Residents are underserved in terms of social and economic factors. Approximately 20% of the population lives in poverty, compared to 14.8% for the United States (US) as a whole.¹⁷ About 40% of the population speaks a language other than English at home.¹⁸ Data also shows that compared to Washington State as a whole, residents in the Valley are less likely to have health insurance, less likely to have a college degree, and more likely to have an educational level less than high school.¹⁹ The Community Need Index (CNI), which measures various socioeconomic indicators known to contribute to health disparities (income, culture and language, education, housing status, and insurance

coverage) for every zip code in the US assigns a score on a scale of 1.0 (least need) to 5.0 (most need). The Valley's zip code scores range from 4.6 to 5.0 on the CNI scale, indicating that people living in these communities experience substantial deficiencies in health promotion and health attainment.²⁰ In response to these deficiencies, a number of years ago, we initiated a community-academic partnership in the Valley.

Fourteen years ago we formed a Community Advisory Board (CAB) in the Lower Yakima Valley to work with researchers on chronic diseases among Latinos in the Valley. The formation of the CAB followed an extensive community assessment where we identified individuals and organizations that were involved in improving the health of Valley Latinos. Many of the individuals invited to serve on the CAB were representatives of organizations that provided services to the Latinos in the Valley. Thus, we included members from the local hospitals, especially the Federally Qualified Health Center, from local food banks, from local schools, from the health district, from the local Spanish language radio stations, and from the local migrant council. The initial collaboration project focused on cancer, especially screening, as well as diet and nutrition and smoking cessation. Subsequently, community members noted the high prevalence of diabetes in the Valley and a project was added to identify and prevent diabetes.

Recruitment

All members of the CAB were eligible to participate in this study. The Principal Investigator (BT) mailed a letter, followed by an email, to all 21 CAB members inviting them to participate in an appraisal of the partnership. She also introduced the bilingual/bicultural external evaluator (SO) who would conduct the interviews. The interviewer then contacted individual CAB members by email. If CAB members wished to participate in an interview, she scheduled a meeting at a date, time and location that was convenient for them.

Questionnaire Development and Data Collection

The project team created an interview instrument consisting of 15 open-ended questions and additional socio-demographic questions. The instrument was designed to 1) describe the individual motivation of CAB members to participate in the partnership; 2) ascertain the perceived role(s) and responsibilities of the CAB members in this long-standing partnership; and 3) identify facilitators and barriers to maintaining participation in the partnership.

The bilingual/bicultural external evaluator conducted one-on-one, face-to-face interviews with CAB members. Interviews were held at the CAB member's desired location: his/her place of employment, the Center for Community Health Promotion (CCHP) field office, or a coffee shop. Participants completed the interview in their language of choice (English or Spanish). Informed consent was obtained at the beginning of all interviews, and socio-demographic information was collected at the end of each interview. CAB members who participated received a \$10 gift card for their time.

Analysis

Each interview was audio recorded and later transcribed verbatim into a Word document. When Spanish (n=1) was the preferred language of the interviewee, the transcription was

translated into English by a certified translator. Interview transcripts were uploaded into Atlas.ti, version 7 for qualitative data analysis (Berlin, Germany). To analyze the data, two independent coders conducted a conventional content analysis approach. This approach is appropriate for topics about which limited background exists.²¹ In line with conventional content analysis, the coders reviewed the transcripts and performed an initial round of open inductive coding, in which no predetermined ideas existed about which codes would be applied.^{21,22} The coders subsequently developed a list of start codes reflective of preliminary emergent themes and each coder coded five specific transcripts using these start codes. The coders identified concepts and emergent themes from the interview data. Then, through an iterative process, the coders grouped similar codes into code families and applied the final codebook to all transcripts. A third coder reviewed transcripts to ensure coding consistency across transcripts.

All procedures and instruments were reviewed and approved by the Fred Hutch Institutional Review Board (File #7293).

RESULTS

A total of 15 interviews were conducted with CAB members between October 2014 and April 2015. The remaining six CAB members were unable to find a mutually satisfactory time to meet with the external interviewer. The majority of the CAB members were female, education levels were fairly high, the average length of time spent on the CAB ranged from five to ten years, the preferred language was English, and the respondents were evenly matched in terms of ethnicity (Hispanic and non-Hispanic White).

We grouped emergent themes into four major categories: motivation for CAB participation, insider knowledge; roles and responsibilities in a community-academic partnership; and perceived challenges and needs for future participation. These are discussed as follows.

I. Motivation for CAB Participation

Participation as a CAB member ranged from one year to 15 years, with 60% of the CAB members interviewed being part of the CAB for 5 years or more. Overall, CAB members expressed motivations to participate in the CAB that included “wanting to help the community,” to contribute their knowledge, experience, and expertise, and to influence the project decisions that had to be made. CAB members stated that their guiding principle for participation in the partnership was to help their communities. CAB members expressed a clear commitment to improving the community’s health:

It’s an important issue, health education, and some of the other members understand and realize, the community that speaks Spanish needs a lot of information, otherwise, things can go crazy. Health concerns are very important, if you don’t take care of your health, disease can spread.

CAB members stated they were interested in bringing health resources and services to their communities and said they could help influence decisions as members of the CAB. They saw themselves as the “voice of the community.” It was important to them to use this voice to help the community.

I know I have this type of knowledge. I want to share it because in sharing through an advisory board at the Fred Hutch, you're also helping the community. The community will also get more information, more learning experiences and if I can be that little leverage, *palanca* [a lever], I'm here...

Others noted that they worked on the CAB, saying "Because of the work I do, it made sense that I participate and ...I know what is going on." Another person noted that participation was built on one's personal experiences: "[It is important]...being able to bring my experience of educating patients and what has worked or hasn't worked. Just working with a population that has a chronic disease, what helps, what doesn't, things like that."

CAB members expressed satisfaction in being involved in the decision-making process, noting they had been involved in a variety of decisions, including financial decisions. For example, one clinic system provided blood analysis for a research project. As another member noted, "I have taken part in discussions...on where funding might go..."

Positive perceptions of the Fred Hutch efforts in the community were a resounding reason for CAB member participation. One CAB member stated, "... I know that they're (the Fred Hutch) doing a good job and my community benefits fairly." Another said, "I like how Fred Hutch makes the community better and that's probably my number one [reason for participating]."

Most CAB members had served on the CAB for five years or more. One major reason cited by CAB members for staying committed was the sense of community that had been built within the partnership. CAB members—who represented diverse organizations in the Valley—appreciated having open and clear communication with other CAB members as well as Fred Hutch staff and investigators. They also valued the presence of mutual trust in each other's areas of expertise and appropriate levels of engagement in the work.

I think about the relationship we have, I feel very comfortable providing input ... it's an open door policy in regards to communications, that we have established over the years...so that the biggest opportunity I have is that I have a great relationship, and we can address issues from both ends [community and academic].

CAB members also cited incentives that motivated their continued participation such as being able to get letters of recommendations, bolstering their résumés, enhancing their networks, and opportunities for professional, personal, and leadership growth.

II. Insider Knowledge

CAB members perceived themselves as having "insider" knowledge about their community. As such, CAB members helped researchers identify topics of interest to the community.

We have the responsibility to give information, so Fred Hutch can better prepare, or think about their target population in relation to what we know about the people we know, we serve, or the needs of the people we serve.

The CAB members' local knowledge helped influence decisions taken by Fred Hutch staff and investigators with regard to prioritizing projects, identifying ways to recruit participants for projects, and reflecting on additional partners to engage in new projects. CAB members

discussed their knowledge of the community, which helped bridge the gap between the research staff and the community members. One CAB member noted, “It’s been very beneficial to the school district, to the families that I work with.” Another CAB member stated, “[It is important] to suggest different avenues of education. Or different variables to consider when working with the population.”

III. Responsibilities in a Community-Academic Partnership

CAB members described their responsibilities at an individual level and also at the CAB level. At the individual level, CAB members said it was their responsibility to act as a liaison between their community and researchers. One CAB member said it was important, “Telling [investigators] what opportunities there are and [to] be an intermediary between them and our community.” As a liaison, CAB members said they were responsible for voicing community needs and providing their thoughts and ideas on the current Fred Hutch research projects. Illustrating this, a CAB member stated, “To serve in an advisory capacity. Because if you have something to bring to the table...it’s the whole idea that you can represent...And they listen to it...”

Additionally, CAB members felt a responsibility to disseminate information about the work in which the CAB was involved. CAB members disseminated resources and research findings through professional networks, but also through discussions with family and community members. One CAB member said, “...You have the responsibility...to be participating and going to health fairs, giving out information.”

When discussing the CAB as a whole, most CAB members described their role as one of advising and implementing. They stated they were responsible for informing staff about the status of research projects being planned and implemented in the Valley. A CAB member stated it was a member’s job:

to make the decisions to really see if our goals are being met and how we are getting there, and if we are not meeting those goals, what are we going to do to change? What have been the barriers to—or what have we done? If we came to a problem, what have we done to resolve it?

They also said that as members of the community, they have information on community needs and priorities, as well as access to the resources and networks needed to facilitate the work of the projects. As a CAB member stated, “We know the population we serve, we have the responsibility to give that information.” CAB members described decision-making processes as both formal, such as voting, as well as informal with all CAB members brainstorming solutions to a problem. Another CAB member added,

We discuss the larger picture or problem, and then we break up into smaller focused groups. And we discuss what we see and our experiences within those groups to help narrow down the greatest needs of the community. And then I think that all the focus groups’ ideas or what they came up with are then shown to everyone, to see which is evident for high priority because each group has mentioned concerns.

CAB members noted they were able to tap into their own networks to support the partnership needs and thereby increase services to Valley residents. As a member said, “It

[the CAB] does provide an exchange of information, networking with other people. It expands peoples' visions and then helps them [the Fred Hutch] with ideas for what they want to continue to do..."

CAB members also noted the responsibilities of the researchers. As one participant stated, it was important that the researcher were "... partnering with various entities in the community that serve/include Hispanics." Others stated that the Fred Hutch has the responsibility to know what is going on in the community and to facilitate cohesiveness of community efforts: "Fred Hutch is very familiar with our chronic disease self-management classes... they understand...we are supporting each other." A perceived key responsibility of the researchers was funding. "They [Fred Hutch] are the ones who had to look for the money, had to look for the resources to even do the research..."

IV. Perceived Challenges and Needs for Continued Participation

CAB members stated they appreciated having open and clear communication with other CAB members as well as with staff and investigators; however, they did express some challenges related to the endeavor. Specifically, they described a lack of consistent and informed instruction of their roles and responsibilities. For example, there were contradicting statements about whether CAB members consistently received such information, with some CAB members stated having received a welcome letter explaining the CAB and its purpose, while others did not recall receiving information regarding CAB member roles and responsibilities. One member noted, "I got a welcome letter that explained what the CAB was about, what they were doing, where the meeting was..." Still, another CAB member noted, "I don't know exactly what my roles and responsibilities are, I just show up."

In general, CAB members said they were aware of few, if any, formalized mechanism (i.e. participation in CAB meetings) or materials through which new members to the CAB acquire the necessary knowledge to become effective and informed CAB members. In order to work through such challenges, CAB members suggested providing materials and information regarding the roles and responsibilities of CAB members to newly recruited community members. As one CAB member stated, "If there was something like a handbook or written materials that would be nice too."

CAB members also described limited communication among CAB members between meetings and in-person communication with Fred Hutch researchers. CAB meetings were held three to four times per year. CAB members suggested increasing the frequency of meetings and communication via email.

CAB members stated they wanted to become more involved with the projects that arose as a result of the community-academic partnership, however, they described several barriers hindering their involvement with the projects. These were mostly time-related barriers and included personal obligations and other commitments, such as work and work-related obligations, personal life, and other outside committees with which they were involved.

Respondents also discussed CAB composition as a barrier for the partnership to effectively address community health concerns. CAB members expressed a need for the CAB to pursue strategic partners, such as males, and other groups to expand the work of the partnership and improve the overall health of the disparate communities in the Valley.

I come down to the suggestions to bring two or three more males into the picture because there are young people now, males, who can add, who can bring in a new sensitivity for example of what the immigrants are going through in our area.

Some CAB members suggested inviting the existing Native American population and new immigrant communities, such as Filipinos, to the CAB. Others suggested that local government representatives, such as city council members, could also provide an important and different perspective as CAB members.

DISCUSSION

This work provides insights into CAB members' perceptions of being involved in a community-academic partnership. The results demonstrate that CAB members have a shared agreement on the role of the CAB as a whole, as well as their role in the projects. CAB members perceived themselves as representatives of the community in the research projects. They viewed themselves as insiders who had special knowledge about their community. They identified their own roles and responsibilities and also brought up responsibilities of the academic partner. In addition, they were able to identify some challenges to working in a community-academic partnership.

CAB members' understanding of their individual roles and responsibilities seemed to lead to their ability to work together for the sake of their community. A perceived strength of the CAB is that members were very aware of their individual responsibilities to the broader community. For example, when they were asked how the CAB as a whole made implementation decisions, they provided examples ranging from how they shaped the research agenda and identified targeted communities, to the integral role they played in voicing the needs of their respective communities, and ensuring research projects were sensitive to the community's needs.

Duran and colleagues recognize that community members who are service professionals and policymakers are attracted to this type of participatory partnership. Selection criteria often emphasize the need to add partners who are already well respected and established in the community.²³ This applied to this work; we found CAB members tended to be well-positioned in high impact and high reach organizations such as the local clinics and the health department. However, CAB members who work in non-profit, social services organizations are also essential to ensuring the project aims are indeed aligned with community needs. As a whole entity, collective skills and attributes appeared to complement each other. Thus, CAB members' expertise served to gather data on the health status of the population and to navigate the intricacies of doing research in the Lower Yakima Valley.

By leveraging the skills and assets of the CAB members, researchers have been able to build a network of relationships that allows for community involvement and trust.¹³ CAB

members' rapport within the community has been indispensable in building trust with the researchers. The CAB is also integral to increasing the awareness of the researchers' institution as more than a cancer research center. It has been the CAB, voicing the needs of the community, that has expanded the role of investigators to target other chronic illnesses in the Valley, including diabetes, pesticide exposure, and childhood obesity.

Community-academic partnerships in research can increase the capacity of community members to create projects that address community needs.²⁴ The partnership in the Lower Yakima Valley integrated CAB members into all aspects of research. The findings from this study provide further understanding of the added value that CAB members bring to a community-academic partnership as we work to reach project goals, such as building community capacity, integrating the community into research, disseminating findings back to the community, and using alternative perspectives to further research goals.¹³ Furthermore, CAB members provide firsthand knowledge that is valued in project decision making.

CAB members also provided recommendations to improve the partnership. One was to implement a formal system for new CAB members to be integrated into the team, including providing role and responsibility specifications. Secondly, they suggested that communications could be more creative given their commitments outside the CAB. Lastly, CAB members noted that the Valley is home to a sizeable Native American population. Attempts to gain access to this group have been largely unsuccessful and more culturally appropriate efforts, such as hiring Native American staff, should be made to include this underserved population. These recommendations have implications for any research working with a CAB for community connection and outreach.

This study has some limitations. This CAB is comprised of representatives from community-based organizations in the Lower Yakima Valley of Washington State and may not be representative of CABs in other parts of the country. In addition, interviews were only conducted with CAB members. In order to get a complete picture of the success of the CAB, it would be useful to have perspectives from other community members, as well as from the researchers themselves.

Conclusions:

Community-academic partnerships have gained traction as a viable approach to integrating the community into all aspects of research, with the ultimate goal of eliminating health disparities. This study supports the use of a CAB to represent the community. By providing their perspectives as a community, CAB members were able to engage academic researchers in a two-way conversation. This dialogue served to fine-tune implementation of partnership principles in this community-academic partnership and helped implementation of interventions move forward. The success of the projects leveraging the expertise of the CAB members in the Lower Yakima Valley illustrates the value of community-academic partnerships. Future research could further explore how community partners involved in a collaboration continue to build on the successes of the work after a project has concluded.

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