J Canc Educ (2013) 28:784–789
DOI 10.1007/s13187-013-0516-7

Focus Group Discussions in Community-Based Participatory Research to Inform the Development of a Human Papillomavirus (HPV) Educational Intervention for Latinas in San Diego

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Abstract The purpose of this paper is to demonstrate the usefulness of formative focus groups as a community-based participatory research (CBPR) method in developing cancer education programs. Two focus groups were conducted according to CBPR principles, in order to develop a community-competent human papillomavirus (HPV)/cervical cancer educational program for Latinas living in the USA/Mexico border region. Focus group participants were 18 female Mexican American community health advisors. Participants reported that there is limited information and many myths about HPV and the vaccine in the Latino/Latina community, along with many barriers to acceptance of HPV/cervical cancer-related information. Furthermore, participants discussed their recommendations for the development of a culturally appropriate HPV educational program. From these data, we have a better understanding of the HPV/cervical cancer educational approach that will be most accepted in the community and what key information needs to be provided to women who participate in the program, which reinforces the importance of the CBPR approach to the formative phase of cancer education program development.

Keywords HPV · HPV vaccine · Cervical cancer · Latinas · Community-based participatory research

Every year in the USA, there are approximately 11,000 new cases of cervical cancer and 4,000 deaths due to cervical cancer [1]. The Latino/Latina population is disproportionately affected by cervical cancer, in that Latinas have higher incidence (12.7 per 100,000) and mortality rates (3.1 per 100,000) due to cervical cancer than non-Latina White women (7.3 per 100,000 and 2.1 per 100,000, respectively) [1–3]. Such disparities are unacceptable, given that cervical cancer is 100 % preventable with medical advances such as the Pap smear, human papillomavirus (HPV) test, and the HPV vaccine. Virtually, all cases of cervical cancer are caused by HPV, and the virus has also been associated with approximately 4–5 % of all cancers [4, 5]. In 2006, the Food and Drug Administration approved the HPV vaccine (Gardasil), which has been found to prevent HPV types 16 and 18 that cause 70 % of cervical cancers and types 6 and 11 that cause 90 % of genital warts cases. A second vaccine (Cervarix) has also been approved to prevent types 16 and 18. The vaccines are available for girls and boys (Gardasil only) ages 9 to 26, and it is recommended that the vaccine series be initiated before sexual activity begins [6].

Although this relatively new primary prevention method has been recommended by federal agencies and covered through the Vaccines for Children Fund, initiation of the vaccine and completion of the three necessary doses remain low [7, 8]. Racial and ethnic disparities in vaccination initiation and completion have been also documented. For example, a study by Neubrand and colleagues reported that

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among 352 girls/young women ages 21 years or younger, 58 % completed the three doses during the required time frame [7]. Non-Latina White women were more likely to complete the three dose series than Latinas [7]. In a study that examined the National Immunization Survey, Latinas were less likely to be aware of HPV and the HPV vaccine than non-Latina women, and fewer Latinas were vaccinated than non-Latina women [9]. Ethnic disparities in uptake are observed despite research that has demonstrated Latinas' positive attitudes toward the HPV vaccine and willingness to vaccinate themselves and their children [10]. This discrepancy suggests a crucial need to know more about how to develop culturally competent programs to inform Latinas about how to protect themselves and their children from HPV and cervical cancer, given that Latino/Latinas are the fastest growing subpopulation in the USA [11].

The community-based participatory research (CBPR) approach has been found to be most useful in addressing cancer-related disparities in underserved populations [e.g., 12–14]. Following principles of CBPR, community and academic culturally diverse partners in San Diego, CA, initiated a HPV Advisory Committee (HPVAC) to guide the process of developing a HPV educational program. The goal was to build capacity in a long-standing community health advisor program [15–19] by developing a culturally competent HPV/cervical cancer/HPV vaccine health curriculum for medically underserved Latinas living in the USA/Mexico border region. The committee decided that an important step in curriculum development should be to conduct focus group discussions with local Latina community health advisors. The goal of the focus groups was to assess perceptions of HPV/cervical cancer/vaccine in the community, barriers to disseminating knowledge, and program recommendations. The purpose of the current paper is to describe the usefulness of focus groups as a formative phase of the CBPR process in developing a community-competent HPV/cervical cancer/vaccine educational program for Latinas living in the USA/Mexico border region. This approach is unique in that it aims to inform needs assessment from a community health advisory perspective.

Subjects and Methods

Subjects

The HPV Advisory Committee recruited 18 participants from their list of experienced community health advisors (*Por la Vida*) who were mothers or caregivers of children aged 9 to 26. Por la Vida (PLV; meaning "for life") was developed in San Diego in 1988 using a CBPR model that has evolved and expanded over time [15–19]. To date, PLV programs have served low-income, low acculturated Latino communities with limited access to health care services in the San Diego border region and beyond. Details about the program have been presented elsewhere [15]. Briefly, PLV "consejeras" (community health advisors or *promotoras*) conduct cancer education classes in small groups, and these programs have been found to be effective in increasing cancer screenings, healthy behaviors, and knowledge about cancer risk factors [15, 19]. More than 250 consejeras have been trained to conduct the cancer education classes, which usually consist of 60- to 90-min weekly sessions over a period of 12 weeks. The program has reached more than 7,000 Latino families in the San Diego/Mexico border region. Currently, there is no educational curriculum about HPV and the HPV vaccine. The HPVAC was convened because the community health advisors had identified a gap in that area and expressed a sense of social responsibility to address the needs and interests of the community in these topics.

Materials

Participants completed a questionnaire (took approximately 20 min to complete) about their behaviors, knowledge, attitudes, and beliefs about HPV and the HPV vaccine as well as demographic questions in order to assess the preliminary translation and its feasibility for use in the future studies with the community. Items were translated from English to Spanish by bilingual staff with over 10 years of experience in translation of health-related information and research materials. Some of the behavioral questions were adapted from previous PLV program assessments and the Behavioral Risk Factor Surveillance Survey [20]. Questions on HPV knowledge were adapted from previous research by Ragin and colleagues [21]; questions on HPV vaccine attitudes and beliefs were adapted from the California HPV Immunization Attitudes and Beliefs Scale [22]. Both measures have been found to be useful in assessing knowledge, attitudes, and beliefs but have not been used with a Spanish-speaking sample. Since the questionnaire was only given to participants to test the feasibility, the items were not quantitatively analyzed.

The focus group questions were developed by the HPVAC, which includes individuals who are experienced in focus group methodology. All questions were critically evaluated and discussed during a HPVAC meeting. The same instructions and questions were used for both focus groups. The questions followed a semi-structured format with open-ended questions as suggested by past researchers [23]. Introductory questions were developed to build rapport and encourage friendly dialogue among participants. For example, participants were asked to introduce themselves to the other participants and summarize their experiences with the PLV program. After introductions, the focus group moderators asked a series of key questions, which included, "What do 'we' know about HPV?", "What would our community want to know about HPV?", "What may be some potential barriers to knowledge of HPV and HPV vaccination?", "What myths have you heard about HPV and the HPV vaccine?", "With whom should information about HPV be discussed?", "How may information about HPV and the HPV vaccine be disseminated in our community?", and "What type of program would be suitable to disseminate this information?"

Study Procedures

The two, 2-hour focus groups were held separately at the same community setting (where most PLV programs take place); a small meal was provided to make the environment welcoming and comfortable. Both focus groups were conducted in Spanish and moderated by one of the HPVAC members with experience in focus group facilitation and as a community health advisor. Three other experienced, multicultural, and bilingual HPVAC members served as process facilitators, collecting detailed notes on group dynamics, key discussion points, and notable quotes. In consideration of the cultural background of the focus group participants, the HPVAC felt strongly that the focus group discussions should not be audio recorded. It was believed that audio recording would make the women feel uncomfortable discussing such sensitive issues and reluctant to disclose information. We considered forgoing audio recording to be acceptable, given the purpose of the focus groups, which was to inform program development. As a result, the decision was made to include three process facilitators, to ensure that quality notes were taken and thorough observations were made, as consistent with the past research to protect sensitivity [23, 24]. In order to check for reliability of the facilitators' notes, the facilitators discussed and compared notes upon completion of the focus group session and then again at a follow-up HPVAC meeting.

The participants completed the pilot questionnaire before the focus groups began. The focus group discussions took place according to the instructions presented above. In appreciation for their participation, participants received a small monetary incentive. After participants left the focus group location, the facilitators had a discussion to debrief and process the focus group findings. Waiver of informed consent was granted from the Institutional Review Board at the sponsoring institution.

Results

Participant Information

Focus group participants were 18 female Mexican American community health advisors who currently work for PLV (described previously). Their experience conducting PLV programs ranged from 10 to 23 years. There were two groups conducted; one group had 4 participants (M age=62.67), and the other group had 14 participants (M age=50.31). All participants had children between the ages of 7 and 43 (M=27.25), and all but one woman had at least one child between the ages of 9 and 26 (vaccine-recommended ages) or were caregivers for children within that age range. Most women were married (70.6 %, n=12) and spoke only Spanish or Spanish better than English (87.5 %, n=14). None of the women had attended any class or program about HPV or the HPV vaccine prior to the focus groups, and only five (29.4 %) had received any pamphlets or information about the topics. Five women (29.4 %) reported that at least one of their children had received the HPV vaccine.

Qualitative Analyses

Qualitative analyses were conducted at two levels: content of group discussion and group dynamics. There were several themes that emerged from the facilitators' focus group discussion notes. One of the most profound themes was that there is limited information and many myths about HPV and the vaccine, which act as potential deterrents to acceptance of HPV/cervical cancer information in the Latino/Latina community. Other themes included perceptions and the use of HPV information sources as well as recommendations for educational curriculum.

Content of Group Discussion

Many Myths and Limited Information About HPV and Cervical Cancer in the Community

The participants reported that they have been asked many questions by previous PLV group participants about HPV and the HPV vaccine and that the participants do not know how to best answer these questions. For example, women attending other past PLV group sessions want to know more about how HPV develops, how it is transmitted, and whether a Pap smear is a test for HPV. Women also wonder what does having a positive HPV test mean; in other words, what can be done about it? How does HPV develop into cancer? Limited reliable information about the HPV vaccine also leaves women confused about the safety and effectiveness of the vaccine, as well as what happens if the three-dose series is not completed. Women were not sure to who the vaccine is recommended for, and what basis those recommendations are made on. The participants expressed that the information provided on TV about the HPV vaccine is not clear and leaves women confused and with many doubts. Along with the limited amount of information, the participants reported that there are many myths about HPV and the vaccine that have been circulated in the community (see Table 1). Participants also noted that children/grandchildren have often come home with

Table 1 HPV and HPV vaccine myths that participants heard in their community

Women can only contract HPV from promiscuous men.
HPV is developed from having interracial sexual intercourse.
HPV is developed from performing sex in different ways.
Pregnant women are most likely to get HPV.
HPV is associated with AIDS.
HPV only happens to women that have multiple partners.
The HPV vaccine will promote sexual freedom.

knowledge about HPV, but it has been hard for parents to determine whether the information they bring home is accurate.

Participants' HPV and HPV Vaccine Knowledge

Some participants had correct knowledge about HPV and the vaccine (e.g., knowing it was given in a three-shot series, vaccinated women need to continue getting Pap smears). Some participants knew that some clinics offer the vaccine for free but did not know which clinics were offering it for free. One group of participants knew that the vaccine was available for women aged 9 to 26 (at the time the focus group was conducted, it was not yet approved for boys), while the other groups thought the vaccine was only for young girls (aged 12–15) that never had intercourse. One participant knew that HPV could be found in the mouth or throat, but others in the group were surprised to hear this.

The focus group discussion revealed important misunderstandings or gaps in the knowledge about HPV and the vaccine. For example, participants knew that HPV was associated with cancer, but they were unsure exactly how HPV developed into cancer. Women also did not know that some types of HPV could cause genital warts. The women expressed concern and confusion over why the vaccine was not being given to older women. One participant disclosed that her pediatrician told her it was because there are not enough vaccines for everyone.

There Are Barriers to Learning About HPV/Cervical Cancer and the HPV Vaccine in the Latino/Latina Community

Myths and misinformation as described above were seen as barriers that predispose individuals to not be receptive to information from public health programs and prevent participation in these programs. For instance, participants in both groups expressed that women in the community may fear that talking about HPV or giving young girls the HPV vaccine would increase sexual freedom, which goes against traditional cultural beliefs (e.g., *marianismo* and its emphasis on sexual purity), and could increase the risk for other STIs. Another cultural factor thought to be a barrier was *machismo* [25], which may lead men to avoid condom use, thus spreading HPV. One participant commented that she watched a show on TV about HPV that gave her the message, "If a woman has warts maybe the husband would think that the wife is unfaithful." Other potential barriers reported by participants were fear of cancer, time constraints, and communication difficulties. Participants reported that HPV was a personal topic and that embarrassment or not knowing how to talk about it with others would be a barrier for these women.

Participants' Recommendations for the Development of a Culturally Competent HPV/Cervical Cancer Program

Participants felt it was important to address the myths and misunderstandings in the community through an educational program conducted face-to-face by trained community health advisors (following the PLV model) in small group settings. Both groups expressed the need to use culturally competent visual aids (including videos) to disseminate the information in the programs because in their experience, visual aids have been valuable in helping the community understand and remember key information. Participants also acknowledged the importance of brochures with visual aids (not sexually graphic) to facilitate discussion between women who participate in the program and their families or other community members. There was a divide between the women in the two focus groups about whether the programs should only include women ("older" group of women supported this) or if they should include women and their families to encourage family communication ("younger" group of women supported this).

Due to the sensitive nature of the topics that such a program would cover, emphasizing confidentiality to the future class participants and community health educators would be important. Participants felt strongly that women in the community lack the necessary skills to discuss sexual health with their partners, children, or other family members and that a successful program should facilitate effective family communication skills. Participants were also concerned that their children/grandchildren often have more information about HPV than the parents do, which challenges children's views of their parents as a source of knowledge and authority and could be inconsistent with the cultural value of *respeto* to the elders. Therefore, the participants stressed the importance of including information in the program that would strengthen women's self-efficacy for talking to family and friends about these sensitive topics. Two other components that participants felt important to include were a question/answer session with a health professional and incorporating the "learning partners" (*compañeras de aprendizaje*) PLV component [19] for women to continue the diffusion of the information into the family and community.

Group Dynamics

Previous researchers have emphasized the importance of noting group dynamics in focus groups conducted with vulnerable populations [23, 26] and have identified different patterns of interactions that often evolve in focus groups [26]. The most common pattern of interaction observed in both focus groups was "dependency statements" or expressions of reliance/compliance within the group. Participants were often looking for validation from each other in terms of the questions asked and relying on each other to answer their questions. Another group dynamic was "pairing statements" or expression of sincerity, friendship, support, or intimacy. Participants expressed these feelings in their description of the current PLV program and what it offers to the community and the social responsibility they feel to be a good source of information to their community. Also present were "counterpairing statements," which are expressions that avoid intimacy or personal information. This dynamic was evident when talking about "others' experiences" with regard to experiences surrounding sexuality, instead of disclosing their own experiences.

Discussion

We conducted two focus groups with Latina community health advisors living in San Diego County in order to understand the HPV/cervical cancer/HPV vaccine information needs of Latinas in their community. The results illustrate the usefulness of focus groups as a CBPR method in planning community-competent cancer education programs. Women (including community health advisors) in this community have limited information and have heard several myths about HPV, cervical cancer, and the HPV vaccine. These findings reinforce the importance of developing linguistically and culturally competent cancer education programs and offer ideas for curriculum development. Based on the findings, HPV/cervical cancer/vaccine education programs in this community should include information about (1) HPV development and transmission, (2) the purpose of a pap smear, (3) how HPV may or may not develop into cervical cancer, and (4) details of the HPV vaccine such as safety, efficacy, side effects, and recommendations. Women should have opportunities to share HPV/cervical cancer/vaccine myths in an environment where these myths can be dispelled and accurate information provided. A careful community health advisor training strategy often used in previous PLV cancer education programs could be particularly valuable in this topic area. Namely, community health advisors should practice discussing potential myths that have been identified in the community so that they are prepared to address them in the program sessions.

Using formative focus groups also helped identify ways to address barriers linked to traditional cultural beliefs that should be taken into consideration during cancer education program development. Apprehension to discuss topics related to sexual health and fears about sexual promiscuity resulting from the HPV vaccine can be explained to an extent by the cultural belief of marianismo and its emphasis on sexual purity. Furthermore, fear of cancer and beliefs in fatalism can influence perceptions about disease and the cause of disease [27]. HPV/cervical cancer educational programs should address these barriers by building women's self-efficacy in their communication skills regarding sexual topics, presenting the research that contradicts the belief that talking about sexual topics will lead to early sexual debut or promiscuity, and informing women about the benefits of cancer prevention and early detection. Women need not believe that HPV will inevitably lead to cervical cancer, and they may take comfort in knowing that it is highly preventable if detected early. In order to address time constraints, such programs should be held at a mutually convenient time, in a mutually convenient location that is easily accessible by public transportation, which is consistent with community-based participatory methodology [12–14] and the standard in PLV community health advisor programs to date.

Following principles of CBPR methodology [12–14], which has been at the core of the PLV programs for several years, the next step is to develop an educational curriculum that will address HPV/cervical cancer and the HPV vaccine in a way that builds on the long-standing strengths of the community. For example, participants emphasized the need to have such programs be conducted face-to-face, in small settings, and led by people who they trust (e.g., established community health advisors). Moreover, interactive skill-building programs that stimulate discussion among the women participating in the groups were thought to be an approach that would be most accepted and successful in the Latino community living in the San Diego border region. According to CBPR principles [12–14] and evidence from previous PLV programs [15–19], providing women with knowledge and skills to communicate accurate information has the potential to influence more than just the individual engaged in the educational programs. We have honored the CBPR process by engaging the community in every step of this research process, and the community voice will continue to lead the implementation and evaluation of the program that is developed.

Although our findings are unique in that they integrate the ideas of experienced community health advisors in the cancer education program development process, they are not without limitations. Our focus groups were not audio recorded, which means we do not have verbatim information about what was shared; however, our process facilitators were trained to be careful observers, and the facilitator debriefing sessions helped to confirm and solidify the observations. We feel that forgoing a situation that could potentially inhibit participants from sharing their thoughts on a sensitive topic provided us with richer and less censored data to inform our program development. In addition, our sample included Mexican American women from an existing community health advisory network in the San Diego/Mexico border region, which means that our findings are not necessarily representative of the Latino community at large, nor can we speak directly to the ideas about HPV of men in the community.

Involving community health advisors is critical to program development, implementation, and evaluation. From these data, we have a better understanding of the HPV/cervical cancer educational approach that will be most accepted in the community, and what key information needs to be provided to women who participate in the program. Consistent with CBPR principles, our HPVAC has conducted a needs assessment in a way that is culturally consistent and has used those findings to create the objectives of the program which utilizes trusted community health advisors with a positive reputation in the community (i.e., PLV). Additionally, our program will incorporate family communication skill building through role playing, which may enhance women's self-efficacy in discussing these important topics with their families. Our findings have helped to demonstrate the importance of using focus groups as a CBPR approach to the formative phase of cancer education program development.

Acknowledgments This study was funded in part by the National Cancer Institute, Comprehensive Partnerships to Reduce Cancer Health Disparities Program, grant nos. U54CA132384 and U54CA132379. We extend our appreciation to the HPVAC members (Cristina Alvarado, Lupita Lombardo, and Guille Coronado) and the community health advisors who participated in the focus groups.

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