2-11-2013

Community - Based Participatory Research with Hispanic/Latino Leaders and Members

Mary Grace Amendola
Rutgers University, mariegraceus@yahoo.com

Recommended APA Citation

Community - Based Participatory Research with Hispanic/Latino Leaders and Members

Abstract

Hispanic/Latinos (H/L) are being studied for healthcare disparities research utilizing community - based participatory research (CBPR). CBPR's active participation of community members and researchers suggests improvement in community health. Yet there are no known studies that inductively investigated the lived experience of H/L community leaders and members with CBPR using interpretive phenomenology. Data were obtained from observations, field notes, biographical interviews, individual interviews and focus groups. The findings supported that community members wanted to collaborate with researchers utilizing the C BPR approach so that culturally sensitive interventions can be created to encourage health - seeking behaviors in their community

Keywords

Hispanic/Latino, Community - Based Participatory Research, Interpretive Phenomenology

Creative Commons License

Acknowledgements

Community-Based Participatory Research with Hispanic/Latino Leaders and Members

Mary Grace Amendola
Rutgers University, Newark, New Jersey USA

Hispanic/Latinos (H/L) are being studied for healthcare disparities research utilizing community-based participatory research (CBPR). CBPR's active participation of community members and researchers suggests improvement in community health. Yet there are no known studies that inductively investigated the lived experience of H/L community leaders and members with CBPR using interpretive phenomenology. Data were obtained from observations, field notes, biographical interviews, individual interviews and focus groups. The findings supported that community members wanted to collaborate with researchers utilizing the CBPR approach so that culturally sensitive interventions can be created to encourage health-seeking behaviors in their community. Keywords: Hispanic/Latino, Community-Based Participatory Research, Interpretive Phenomenology

Hispanic/Latino's (H/L) represent 14% of the United States (U. S.) population and are the fastest growing groups of immigrants. Diseases that H/Ls suffer disproportionately include diabetes, heart disease, HIV/AIDS, cancer, stroke and obesity (Addressing Racial and Ethnic Disparities in Health Care, 2001; Dallas, 2004; Hispanic/Latino Fact Sheet, 2009). According to Angeles and Somers (2007), Hispanics are less likely to receive care for diabetes and are two times more likely to die from the disease than non-Hispanic whites.

As the H/L population continues to grow, the traditional standard approach of addressing health issues in clinical terms, and the way illness is defined in relation to individual behavior, is inadequate (Bryant, Raphel, & Travers, 2007). Not all people have the same healthcare and cultural needs. It is especially important to understand the quality of life in the cultural context and patterns of a community in order to deliver proper healthcare. Paying attention to the H/L cultural needs will also assist in eliminating health disparities (Flaskerud, Lesser, & Dixon, 2002; Leininger, 1994).

Increasingly, an alternative approach, community-based participatory research (CBPR), is being utilized for health disparities research in communities. CBPR is active participation of community members and researchers collaborating in the planning, implementation, and evaluation of research; its principles encourage more equitable collaboration, enhance the contributions of others, improve health, and ensure culture sensitivity (Freire, 1993; Israel, Schultz, Parker, & Becker, 1998; Israel, Schultz, Parker, & Becker, 2001; Wallerstein & Duran, 2006). An essential component of CBPR is empowerment. When people successfully identify a need, and design, implement, and evaluate their intervention, they have a sense of hope in having successful outcomes (Freire, 1992) and feel they are capable of constructing and using their own knowledge to problem-solve (Freire, 1993; Reason & Bradbury, 2006; Wallerstein, 2002; Wallerstein & Bernstein, 1988; Wallerstein & Duran, 2006).

The purpose of this study was to inductively investigate the lived experience of CBPR with H/L community leaders and members utilizing interpretive phenomenology. There were many studies that described the challenges and obstacles in conducting CBPR with H/Ls by evaluating the CBPR process and their experience with it (Balcazar, 1991; Bent, 2003; Farquhar, Michael, & Wiggins, 2005; Foster, 2007, Goodwin, 2008; Lopez, et al., 2007; May

et al., 2005; Parrado et al., 2005; Rhodes et al., 2007); however, as of a 2009 literature search there were no known studies that inductively investigated the lived experience with H/L community leaders and members utilizing CBPR.

The first aim of this study was to describe and interpret the lived experience of community leaders and members with CBPR. Community leaders and members were interviewed to share in detail their experience with CBPR by using van Manen's (1990) hermeneutic phenomenological approach and Paulo Freire's (1993) critical social theory (CST). The objective of using van Manen's approach was to investigate the essence of their experiences and to present a clear description and interpretation of the life-world of the participants with CBPR. van Manen stated: "Essence may be understood as a linguistic construction, a description of a phenomenon." He also expressed: "A good description constitutes the essence of something so that the structure of a lived experience is revealed to us…. we are able to grasp the nature and significance of this experience in an unseen way" (van Manen, 1990, p. 39). This type of application offered the participants a chance to describe their experience with CBPR in their own words.

The second aim was to have the participants be involved in a dialogue process by sharing their experience as a group with CBPR. The objective was to have the participants use Paulo Freire's (1993) critical social theory as a framework to guide their discussion. Problem-posing was employed as the concept because it embodies the following: participation, open communication, critical inquiry and analysis. Participants looked at the CBPR process, defined the process, analyzed it, and came to recognize the benefits and obstacles of this type of approach and their experience with it. According to Freire (1993), this type of process empowers the participants because they are formulating their own conclusions, and as a result of this empowerment, they are liberated. The participants have gained what Freire calls "conscientizacao," or consciousness; individuals have awakened their consciousness. As a result of this, the participants extracted logical decisions of what should be, by analyzing their experience and interpreting it into action. Freire (1987) states: "Once man perceives a challenge, understands it, and recognizes the possibilities of responses, he acts" (p. 39). In this case the participants in this study are taking action by creating a culturally-specific HIV/AIDS video for their community.

A phenomenological study of community members and leaders experience with CBPR was planned to provide the answer to the following research question: What is the lived experience of Hispanic/Latino community leaders and members with community-based participatory research. The findings to this research question may also provide insight and answers to the following questions:

1. What do the participants think about this approach?
2. Will this approach help them succeed in their culturally-specific HIV/AIDs intervention?
3. Is this approach suitable for the participants and the community they live and work in?

Answers to these questions can determine whether or not CBPR is a type of approach that is applicable and advantageous for this H/L community.

Contextual/Background Information of Community

The location of this study was a rural New England community. Yet, unlike many rural areas in the U.S., it has an urban character. It was categorized as rural because of its farming industry and separation from other population centers. The U.S. Census Bureau (2003) defined this rural community as a "micropolitan" area and the Human Resources and

Services Administration's (2005) qualified it as being rural. The town was culturally varied with a significant H/L population comprising 39.8% of the total population of 17,737, including the following subcultures: Puerto Rican (26.4%), Mexican (9.0%), Cuban (0.2%), and other H/L subcultures (4.2%) such as Guatemalans and Dominicans (Census, 2010). New waves of H/L are Mexicans migrating to this area. Their main employment was as migrant and seasonal farm workers. There were several farms in the area that employed these immigrants. This community had the 12th largest group of H/Ls in Connecticut and the 34th largest population in the New England states. When examining Hispanics as a percentage of the total population, this community ranks third in the state (Census Bureau, 2005). In 2004, the Connecticut economic and community development commissioner identified it as one of the 25 "distressed municipalities." This was based on demographic and economic indicators. Secondary demographic data sources support that this H/L community lived under challenging socio-economic conditions that were not favorable to health. Forty-nine percent of the H/L population over 25 years of age had not completed high school or earned a GED, and 38% of youth between 16-19 years of age were not in school and had not completed high school or their GED. Twenty-five percent of H/L children (5-17 years) lived in homes that were linguistically isolated, while 83% or more of the homes spoke Spanish at home. The community also met federal criteria for a "medically underserved population" (Census Bureau, 2005).

This community had many strengths found in its varied service agencies. They included a high school bilingual education program, Even Start morning preschool (with mothers participating in GED and ESL classes), the Ana de Burgos Poetry Park & Cornerstone Press (a venue for performance and publication of adult and children's' poetry and literature), an area arts collaborative, community soup kitchens, local church initiatives, and the close proximity of two universities (Amendola, 2005). Other strengths of the community's social services included a community health center, hospital, visiting nursing agency, senior services, regional counseling center, substance abuse and mental health agencies, women's center, housing authority, and many others. Some of these agencies reported that they were hiring an increased number of Spanish-speaking healthcare staff.

Another area of community strength was its communication services. Community members were able to experience a local college university radio station that featured a Sunday program broadcast in Spanish, word-of- mouth communication when to vote, 96 percent access to a telephone (including a cell phone), and having access to the Chronicle daily newspaper (Amendola, 2005).

Researcher's Presence in the Community

Having a presence and being involved in this community for four years helped this researcher cultivate community members' trust. Developing trust was time-consuming but worth the effort as it created effective partnerships and helped to keep partners together even without specific funding (Israel et al., 2001). This contributed to community leaders and members inviting this outside researcher to participate in their HIV/AIDs intervention project. They expressed that they had some knowledge about research methods but would like to have a knowledgeable researcher on their team. This researcher agreed to participate for two reasons: (a) to gain an understanding of the experience of community leaders and members with CBPR, and (b) to be of assistance and support to the community with their HIV/AIDS project. This research study was accomplished by conscientious negotiation and establishing a trusting relationship, a key practice in developing a successful research venture for all involved. The participants agreed to be involved, with the awareness that the purpose of the

study was to gain an understanding of the lived experience of community leaders and members with CBPR.

It is important to note that this researcher was predisposed to knowing about the phenomenon of CBPR due to the existing bodies of scientific knowledge with CBPR and experience working in this community for four years. Husserl (1970) believed that the researcher should "bracket" their knowledge of the phenomenon. He stated that the researcher "must take hold of the phenomenon and then place outside of it one's knowledge about the phenomenon" (pp. 33-42). van Manen (1990) asks "how does [the researcher] put out of play everything one knows about an experience that one has selected for study?" (p. 47). He recommends that the researcher "comes to terms with [their] assumptions, not in order to forget them again, but rather to hold them deliberately at bay" (p. 47). This researcher followed van Manen's suggestion and further explored the literature of experts of CBPR, and noted that the majority of literature did not address the question of the meaning of CBPR with H/L leaders and community members. Instead, the studies tended to describe the challenges and obstacles in conducting CBPR with H/Ls by evaluating the CBPR process. However, it was important to gain an understanding of the lived experience of H/L community leaders and members with CBPR, and to examine the CBPR process as it developed during the collaborative partnership with them. An in-depth understanding of CBPR with H/L leaders and members could bring researchers closer in appreciating the description and interpretation of what CBPR means to the H/L community.

Method

Research Design

A qualitative research design utilizing van Manen's (1990) method of interpretive phenomenology and Paulo Freire's (1993) critical social theory (CST) was used for this study. Phenomenology assisted in describing, interpreting, understanding, and uncovering the meaning of the lived experience of H/L community with CBPR. Critical social theory helped the participants be involved in a dialogue process by sharing their experience in a group using the concept of problem-posing, which embodies participation, open communication, and critical inquiry (Freire, 1993).

The philosophical underpinning of van Manen's (1990) method of interpretive phenomenology involved the traditions of Husserl's (1970) philosophy of descriptive phenomenology and Heidegger's (1962) philosophy of interpretive phenomenology. Husserl (1970) believed that a person could develop a description of their experience through consciousness and intentionality, and that the mind and body function as one rather than two separate parts. He also developed the process of reduction or bracketing involving deferring the researcher's judgments or beliefs about a phenomenon in order to see it clearly. Heidegger (1962) stressed that interpretation was vital to the process of understanding. He highlighted the fact that every unexpected meeting with someone required an interpretation of their background or history because it influences their lives. Heidegger did not agree with Husserl's bracketing, believing it was impossible, as there was no distinction between the individual and experience; they co-exist, and are inseparable (Heidegger, 1962).

van Manen's (1990) six step method of hermeneutic phenomenology was utilized in the project. van Manen (1990) described this research method: "As a dynamic interplay among six research activities" (p. 30). The steps as described by van Manen are as follows:

> Turning to a phenomenon which seriously interests the researcher and commits
> them to the world;

Investigating experience as we live it rather than as we conceptualize it;
Reflecting on the essential themes which characterize the phenomenon;
Describing the phenomenon through the art of writing and rewriting;
Maintaining a strong and oriented pedagogical relation to the phenomenon;
Balancing the research context by considering parts and whole. (van Manen, 1990, pp. 30-33)

In step one, this researcher chose the topic of CBPR as it is a type of research that was well-suited for this researcher because of its active participation with community members in the collaborating, planning, implementation, and evaluation of research. The commitment to the phenomena necessitated a huge amount of time and resources, including the distance traveled from the researcher's home in Rhode Island to this rural community in New England, Connecticut. As described in the gaining-access section, four years were spent in the community prior to the beginning of data collection.

Step two required reading the literature on CBPR and the H/Ls health, and culture. It also necessitated observing and spending time with the participants and their family members, recording field notes, and taking photos while on foot in the neighborhood, which allowed this researcher to enter into their life-world. This also helped this researcher transition from an intellectual level to a personal place where the participants lived and/or worked.

Step three, was the initial analysis, and included individual interviews conducted at the participants' homes. The participants discussed and reflected upon their transcripts, and the essential themes that emerged. The participants were then asked to return as a group to discuss the essential themes.

The focus group was conducted at the community leader's office space in the community. The participants were asked to do the same as in their individual interviews. These individual interviews and focus groups, according to van Manen (1990), are known as hermeneutic interviews, where the researcher goes back "again and again" to the participant to dialogue about their transcripts and essential themes, which allows [and promotes] the participants to be collaborators of the research project (p. 44). van Manen (1990) also stated: "Reflection on the text [transcripts] of previous interviews [are needed] in order to aim for as much interpretive insight as possible" (p. 99).

The researcher also tested her work by sharing the themes and text with her committee members (van Manen, 1990). When themes are established and finalized, they should take hold of the essence (van Manen, 1990). van Manen stated: "In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (p. 107).

In step four, the text in a hermeneutic research study is written and rewritten. This process was to perfect the description of the meanings of the H/L leader and community members experience with CBPR. Steps five and six maintained a pedagogical relationship with the phenomenon of CBPR by taking into consideration the parts and whole of the research context. To make the text more interesting and "come to life", reflections of conversations with the participants were integrated into the phenomenological text, accompanied by photographs of the community and participants, along with field notes.

Gaining Access

The researcher participated in many activities with this community for four years prior to this research study, such as assisting in coordinating a health fair with community members and local agencies, developing surveys, and presenting research findings at community forums. Having this relationship with the community helped in gaining access and also helped

establish two of the functions/processes in step one of CBPR: finding a community partner; as this researcher's major advisor had previously established a community partnership and a previous community assessment had also been conducted. This researcher updated the assessment in a graduate community health course (Kelly, 2005).

CBPR has three primary steps, identified in Table 1. Step one has six components. Step two, the acting cycle, are the projects activities performed by the participants. Step three, the review cycle, where the researcher and the participants come together to assess the process and the outcomes of the research.

Table 1. CBPR Primary Steps

Primary Steps	Functions/Processes
One	1. Finding a Community Partner 2. Resources 3. Community Assessment 4. Institutional Review Board 5. Formalize arrangements with community-partner 6. Planning Cycle
Two	1. Acting Cycle
Three	1. Review Cycle

Sample/Setting

Eight community members participated in this study. It was a purposive sample of a H/L community leader and community members. The community leader assisted this researcher in recruitment of community members by snowball sampling. Inclusion criteria for these participants were: (a) Hispanic/Latino; (b) speak, read, and write English; (c) 18 years of age and older; (d) agree to participate; and (e) give consent.

Eight participants, six men and two females, agreed to be interviewed for the study. Their ages ranged from 32 to 59 years old. They were from the following subcultures: Mexican (1), Argentinian (1), Dominican (1), and Puerto Rican (5). Six participants were outreach workers. Outreach workers provide services to particular segments of a community (Houghton, 2009); for example, educational outreach to H/Ls migrant workers regarding precautions when working with pesticides. One participant was a pre-cook at McDonalds, and the other participant was a maintenance technician for a military base. However, these two participants also volunteered as outreach workers for their religious organizations. The participants' educational level was from ninth grade to four years of college.

Evolution of Participants

During the course of two years, two community leaders left the group as one of them had limited time and the other, unfortunately, had a drug relapse and could no longer participate. Some community members also left for similar reasons of time constraints and family issues. Each time a participant left the group, the researcher had to meet with potential participants several times to gain trust and to explain the goal of the researcher's and the group's project. The researcher then had to educate the new members regarding the CBPR approach and critical social theory. Approximately 16 community members were educated during these two years. This was a time-consuming and frustrating process for this researcher.

An entry in the field notes described the researcher's experience as being on an emotional "roller coaster." For several months, just as things were moving upward, a sudden setback would take place.

The community leader that remained in the group assisted this researcher in recruiting new community members. There were eight participants who had been with the group for one year. The group named themselves: The Latino Leadership Research Project (LLRP). This researcher assisted them in developing their booklet containing their mission statement, plan for their HIV/AIDS awareness project, and biographies. This booklet was created for two reasons: (a) to keep the group focused on their project, and (b) to illustrate to potential stake holders that the LLRP had a plan.

One of the entries of the field notes described the researcher as questioning faith in this study's completion. There would be times when only one or two participants would attend, and sometimes no one would be there. Words of reassurance by the remaining community leader, via e-mail and personal conversations, and consulting with the committee, helped this researcher to "keep moving forward." They encouraged this researcher to be direct with the group, asking them if they were truly committed to the project.

The lesson learned from this experience was that this type of research is not linear, and that patience and perseverance is needed. It is essential for researchers to be flexible, non-judgmental, and most of all, to adjust to the community's time schedule.

Data Collection

Before collecting data, approval from the University of Connecticut's internal review board was obtained to conduct this study. The participants signed an informed consent form to participate and to be photographed.

Data collection included participant/close observations, field notes, biographical interviews, individual interviews, focus groups, and photographs of the participants. The interviews and focus groups were conducted at the community leader's office conveniently located in a Christian store on historic Main Street. Occasionally the participants would meet at a favorite local restaurant of their choice, or at a participant's home. This historic street was strongly influenced by H/L culture. There was a Puerto Rican and Mexican restaurant, several barber shops, and hair salons, that catered to H/L men and women (at any given time, H/L music was heard from the barber shops). There were grocery stores that provided H/L cultural foods and products, and some H/L social services. This neighborhood was also in the process of "gentrification", transforming the neighborhood into a wealthier one by modernizing the buildings and houses.

An audio recorder was utilized for all interviews and focus groups. The participants also received a $20.00 grocery gift certificate of their choice for each time they met with the researcher, totaling $120.00. The tapes from the interviews and focus groups were transcribed by a transcriptionist and by the researcher. The backup tapes were stored in a locked file.

Data Analysis

van Manen's (1990) six-step method of interpretive phenomenology was used for the analysis and interpretation of transcripts. The data were analyzed simultaneously with collection. This concurrent method allowed for critical examination of the data.

van Manen (1990) discussed three approaches in the identification of the thematics of a phenomenon: The first approach is wholistic or "sententious" approach observes the text as a whole and allows the researcher its interpretation. The second approach is a discriminate or "high-lighting" approach recognizes words, phrases, and sentences that come to view as vital

to the experience (e.g., the researcher reads the phrase of the participants and the researcher asks: "Are there any phrases that stand out? Can we select some sentences or part-sentences that seem to be thematic of the experience;" van Manen, 1990, p. 94). These themes and titles emerged from the transcripts, and some of the participants words were incorporated into the themes titles (see Table 2 for examples of this). The third approach is a thorough line by line approach looks at every sentence or sentence grouping inquiring what it discloses about the phenomena of study (van Manen, 1990). This researcher used all three approaches to provide more rigor in the analysis of the data.

Table 2: Participants Quotes and Research Themes

Participants Quotes	Research Theme
"It allows us to get to know our community with a deeper understanding."	CBPR Provides a Deeper Understanding of the Community
"Participation is key but so is involvement in the project."	The "P" in CBPR Equals Involvement
"Collaborating and conducting research using CBPR with the researcher gives voice to our people."	The "R" in CBPR is Needed in More Ways than One
"This approach allows us [participants] to identify a health need and we have control over the project, eventually, give it to the children and parents."	"CBPR is Similar to Outreach Workers Job but with Added Steps
"I think this approach is going to help the cultural aspect."	CBPR "Opens the Door" for the Hispanic/Latino Culture
"It's benefit, it empowers the community, it's challenge, time consuming"	CBPR has its Benefits and Challenges

Methodological Rigor

To guarantee the trustworthiness of this phenomenological method, the following established criteria by Lincoln and Guba (1985) was utilized: (a) Credibility—direct sources of proof or knowledge from the participants within the context of their environment and their "truths" or beliefs of what was accurate regarding the participants experience with CBPR; (b) Dependability—reliability of data over time and environments (i.e., can the findings be replicated with similar or same participants in a similar or same context); and (c) Confirmability—documenting precise statements and direct observational evidence from the participants; (d) Transferability—do the findings from the study have similar (not the same) meanings to be transferred to another related environment or situation (Lincoln & Guba, 1985).

The intent of the study was not to create generalizations, but rather to document, understand, and validate the patterns, meanings, attributes, symbols, metaphors, and other data, related to the domain of inquiry being studied; and extracting from the participants' data. This was then brought to the participants, as a process known as member checking, that provided evidence of credibility, and is similar to "internal validity" in quantitative studies (Lincoln & Guba, 1985). In addition, the participants were given a hard copy of the findings to read. This researcher's major advisor and associate advisor confirmed the steps taken by evaluating the researcher's note cards, transcripts, and chart. See chart below.

Results

This study supported that community members wanted to be involved and collaborate with researchers using the CBPR approach to address their identified health need of HIV/AIDs. Six themes emerged to describe and interpret the participants' lived experience with CBPR: (a) CBPR Provides a Deeper Understanding of the Community, (b) The "P" in CBPR Equals Involvement, (c) The "R" in CBPR is Needed in More Ways than One, (d) CBPR is Similar to Outreach Workers Job but with Added Steps, (e) CBPR "Opens the Door" for the Hispanic/Latino Culture, and (f) CBPR has its Benefits and Challenges.

Theme 1: CBPR Provides a Deeper Understanding of the Community

The participants described CBPR with adjectives such as: "realistic, not forceful, flexible, sensitive, makes room for our culture, educational, give and take of knowledge, strength, hope, equality, power, global, sustainable, and makes a difference in peoples lives." All of the participants unanimously agreed that the CBPR approach was instrumental in many

ways, such as assisting them in attaining valuable knowledge about their community; providing them with a better understanding of each other, the agencies they worked for, and would prepare and provide direction with their HIV/AIDs project. Collectively, the participants' expressions were of joy and hope when describing their experience thus far with CBPR and for the future of the project. The community leader stated: "What I saw with CBPR was that it organizes the community in a way that gives them direction, hope, understanding, and education that is going to empower them."

One of the functions of CBPR is to conduct a community assessment. This assignment was given before the participants were to become actively involved in the project. The participants and researcher discussed who would take what part of the assignment. This was based on two criteria: (a) the assessment of the researcher who recognized each participants strengths, and (b) the participants suggesting that it would be best to conduct the community assessment based on their working relationship in the community. For example, outreach workers were paired together, a Pastor was paired with the volunteer HIV/AIDS peer educator/pastoral counselor, and three of the participants were comfortable with performing computer-based research together, collecting demographics of their target population from local, state, and national statistics of HIV/AIDS. Other participants were comfortable in conducting community mapping as these participants lived in the community. Community mapping involved going out "on foot" into the community to answer specific questions regarding the neighborhood, utilizing an observation report form to help accomplish this task.

As a result of this process, participants responded that conducting a community assessment provided a deeper understanding of the community they lived and/or worked in. This researcher wanted the participants to have this experience so that they could have the tools in conducting other community assessments for future projects. They communicated the following: "It allows us to get to know our community better because some of us are not from this community…I just came into this county last year as an outreach worker." This participant's partner expressed: "It's a good thing, so far my understanding has blossomed since the first day, and my understanding of the community is more focused." Another participant who had the assignment of collecting HIV statistics stated: "We are learning and experiencing all different aspects of the community, it is good that we are taking different parts…we are learning something different from each other about the community"; and his partner, voiced: "As far as gathering data, relatively new for me, I have never participated in a project like this, gathering information about the community."

Other participants also expressed that they learned more about their community than they had known before. Two of the participants who had the assignment of community mapping reported: "I went there to do the research, and I know what is what…, it's very important to knowing the community, knowing where the concentration of problems are, and I can go exactly to that right point." This participant's partner reported: "I learned a lot about the community doing the assignment that I didn't know"; and he also added: "…I come from the streets and this is not new for me to walk the streets and do this assignment." The participants also reported that utilizing the CBPR approach for the project of HIV/AIDs would bring their community to a greater level of awareness about the disease because they would be bringing the community information not known to them. One participant disclosed: "It would be an awakening to the community because a lot of people in this community don't know about HIV/AIDs."

It was evident by the participants' expressions how amazed they were in discovering new findings about the community they lived and worked in. One participant shared: "I am learning what is in the community, number one, and that is powerful." Having these specific assignments and going through the iterative process of CBPR helped the participants realize

that in order to make an impact in the community, the parents and children had to participate and be involved in their HIV/AIDs project.

Theme 2: The "P" in CBPR Equals Involvement

All of the participants reached a conclusion that in order for the HIV/AIDs project to be successful, participation of community members (parents and their pre-adolescent children) was essential and believed that involvement was a necessary element. In a focus group discussion of CBPR, the participants voiced: "…the participatory aspect of this is key and in order for this research to be genuine, we need the community involvement." The participants also strongly stressed that when community members are involved, it will motivate and obligate them, including encouraging the participants to be pro-active in doing something constructive in their lives and for the community. One participant gave an example of comparing the agency he worked for, with CBPR: "It's an approach that involves the community… clients feel that case managers are doing everything for them." Participants also spoke very passionately about how important it was for the parents to be involved, especially when it came to their children. One of the participants voiced: "You can't just come in and lecture with this particular culture, about their children…it's really good to have the involvement, and that's what motivates them to talk." Another participant shared in an individual interview, what participation and involvement meant to him: "It has made me work more, made me get more involved in the community…It is important to do this so that I can pass on the information…to get more people involved, to empower them with what we know." The participants overwhelmingly expressed that CBPR brings the community together through its participation and involvement in "getting the message across regarding HIV/AIDs. This participant went on to say: "I think this approach can get the message across, being all involved, rather than at a distance or at the lab, stay in the mix; once the involvement is not there, the message has not been set strongly enough."

The participants expanded on how their participation and involvement created an environment that promoted learning: "We all learn from one another, because we are learning and experiencing all different aspects of the community." The participants also conveyed that as a consequence of this new-gained knowledge, community members would be able to help structure a healthcare system that would be more conducive to their cultural healthcare needs. One participant shared:

> This whole approach is for them [community members] to be involved in the community, and this is important for people to see. They will recognize that it will help build a structure that we need." Another participant reported: "This approach is a good way to help our community, I like coming together, more than good, it gives the community power.

It was clear in all of the interviews that the participants recognized that having community members participate and be involved in all aspects of the project would empower the community. The participants also added that the research they were conducting with the assistance of the researcher would also make a contribution to empowering the community.

Theme 3: The "R" in CBPR is Needed in More Ways than One

Each one of the participants described their experience and need for research and for a researcher, to make their project successful. The participants' related this research and the researcher to the third principle of CBPR: CBPR facilitates a collaborative, equitable

involvement of all partners in all stages of the research (Israel et al., 2001). One of the participant's shared: "The main foundation for this type of research is that you are equal to the people you are working with down in the trenches, it's not a high and mighty thing."

The participants also expressed that research is needed to learn about the "trends" of HIV/AIDs so that they could transfer this knowledge to the parents. This would assist them in demonstrating to the parents how fast the disease is spreading to the youth and possibly to their own children. Many of the participants described trends as a means of "enlightment" for the parents. As one participant stated: "I think this is going to be a really good way to learn about the trends of HIV/AIDs, especially to teach the parents, and bring some enlightment."

Participants reported that another need for research was that it had the capacity to connect people in a way that promotes power for the community. As one participant shared: "It's good, it's powerful, to target our population, the youth, about HIV. It gives the community power, and…this type of research has me with the needs of the people…" Another participant expressed: "This is my first time doing anything like this [research]. I think this is a good thing, it empowers me and gives me strength to work with the community…"

Participants then went on to explain the necessity and value of having researchers engaged in the community. They communicated with profound sincerity that they could use the researchers as a resource to guide them with the project. The community leader reported:

> The way you [this researcher] have built up our capacity to understand this approach…you trained us, you shared with us your knowledge…having that resource, you…, if we had any doubt or any question on a survey that we may have asked wrong, or if we need to keep a question open-ended or closed.

All the participants explained that researchers were needed to provide structure, leadership, and encouragement so that the project would be successful. One participant shared: "There is a lot more structure with a researcher, and covers more angles, which makes me feel that the project is going to be successful." Repeatedly the participants shared that a researcher was needed to "keep things together." During the focus group discussion a participant stated: "Keeping it together, with your experience…, you bring us confirmation that this could be done…You stay on top of it with the e-mails, the phone calls, and all that plays a part."

All of the participants expressed that a researcher was also needed to support and assist individuals and the community to expand in areas of their life where they were lacking competencies, such as education and/or to help build upon their current strengths. Whole-heartedly, a participant stated: "The results of knowing you and gaining the knowledge, that encouraged me to go to college, and that, no matter what way I look at it, it is a blessing…and I am doing my ministry through this approach your teaching us." As the participants spoke of the significance of research and having a researcher collaborate with them on the project, it evoked the realization that their work as outreach workers was similar to the CBPR approach. Also, CBPR had additional steps which made their roles much fuller and richer.

Theme 4: CBPR is Similar to Outreach Workers' Job but with Added Steps

Six out of the eight participants were employed as outreach workers. The other two participants had different jobs but volunteered as outreach workers with their religious organizations. Individually, and as a group, the participants described CBPR as having similarities of how they performed outreach in their community, but with an added step: that of having community members be involved with them in helping to solve the problem of

HIV/AIDs in the community. The agencies where they were employed did not allow the aforementioned to authentically happen, such as CBPR. One participant shared: "This type of approach is similar to what we do as outreach workers, and that is to bring to the people a level of awareness, but with CBPR you have community members involved." Another participant fervently expressed: "We are taking it [HIV/AIDs project] to another step…getting the parents and youth involved in making the video. *This is an additional step that I don't do with my work as an outreach worker."*

Another added step was that the CBPR approach permitted an opportunity for more open communication with one another. Participants described that open communication strengthened and made things more transparent concerning themselves, the community, and the project. One of the participant's said with confidence: "This project has strengthened us, we communicate a lot more, and we know we want the same thing for the community." The community leader then expressed: "This here project has brought together the different pieces of different organizations in the community…It has strengthened us and made us more cohesive." He also emphasized that although their agencies were educating the community about HIV/AIDs, they were not targeting the pre-adolescents and their parents about the disease, as they should, and this was another step that they were doing that their agencies were not. He stated: "The target population that we are reaching, we could prevent it [HIV/AIDs] at this level with this intervention…That's something that no one is doing right now, not even our agencies."

As the participants' project was independent from the agencies the participants worked for, they experienced more control over the project, and were able to be independent thinkers. One participant disclosed: "This approach allows us to identify a health need and we have control over the project, eventually give it to the children…" Another participant added that this project was coming from the "bottom up" and not the "top down", and expressed: "We do what we need to do. The people at the top are separate from us; they don't look at the big picture …"

The participants also expressed that another added step was the research component. They came to the conclusion that having this research training made them more valuable to their agencies, and could possibly advance them in their agency, or lead to other job opportunities. When the participants spoke of advancing themselves, they spoke with much hope and promise for their future careers. One of the participant's shared: "We have more skills for our employment agencies." As the community leader further elaborated: "What makes you more valuable is the information; it takes you to a whole different level. I'm looking at becoming a commissioner" [of a mental health and substance abuse department]. The participants were positively affected by the research aspect of CBPR, and believed that having these research skills would open more doors for the H/L culture to have leadership positions, so that they could advocate for social change in their community.

Theme 5: CBPR "Opens the Door" for the Hispanic/Latino Culture

It was clear in all of the interviews and focus groups, that when the participants reflected upon their past and current experiences of their lives, they felt oppressed as a culture, and frequently spoke of it. They described that they felt oppressed and excluded because they were not part of the decision-making process in areas of education, health, and politics. One participant explained with frustration:

> The door was closed, we are not privy to decision-making that affects our community,be it politics…Politicians will only come around during election time…, and it's about community. What are you doing for our community?

> When are you coming back to our community? Why don't we get answers that we need in our language? When we come to see you, we can't find you or it seems when we come around as a unit, people run.

However, participants expressed that CBPR would "open the door" for their culture because they would be included in the decision-making process. The participant explained:

> What it does, CBPR brings our feelings, our education, our expertise, to the table, and when we're at the table, we can express ourselves…and be passionate as we can be, because what our community does not say, we say it as researchers. We are representatives of the community.

In an individual interview the community leader disclosed:

> People are dying from unnecessary reasons…My mind has been open to this theory and approach [CST and CBPR], it is real and it works. People give up…they are under a system that they don't know how to operate, and if that system fails them, they feel that there are no other options for them…

Participants also explained that CBPR would "open the door" for their culture to be seen as "humans" who want to be treated with "respect" and "dignity." When the participants spoke of this, they presented with much emotion. One participant voiced: "How could you say that this group of people [H/L] doesn't have the right to get benefits, and others do? This type of approach will make them see [the system] the people they are working with seen as humans."

When many of the participants spoke of how CBPR could "open the door" for their culture, they became more animated and expressed that they could not "give up" on their culture because they could see the potential in them. The participants believed that CBPR provided a sense of "hope" for their community. The community leader ardently stated: "This approach, is something we definitely need to empower themselves [community members] and to look within themselves for their resources that they already have."

The participants continuously spoke of how important it was to recognize that H/Ls come from different subcultures and that acknowledging this really helped them to better understand the subtle differences of the other subcultures so that they would not "offend" anyone. A participant shared: "In this community, we have the Dominican culture, Puerto Rican, and we are all Latinos, but we come from different cultures. A lot of people are from Mexico now; in this community…they are different from me being Dominican."

The participants also articulated that it was very important to understand the different H/L subcultures so that they could communicate with them effectively. Many of them gave the example of asking appropriate questions about HIV/AIDs to the parents and children, as this was a very sensitive subject matter. One participant shared: "Although we are all Hispanics, we have different backgrounds; we can all work together in understanding the community better."

As a unit, the participants agreed that although CBPR "opens the door" for their culture, and that the project is focused on H/Ls, they also made it clear that they did not want to discriminate against any other cultures, especially when it came to the children. One of the participants shared: "What is good about this approach, with our intervention, is that we are focusing on Latinos…but we will not leave any other nationality out."

Individually, and as a group, the participants were appreciative that the CBPR approach "opened the door" for their culture, and that it had many benefits; however, they

were also aware of challenges they would be personally confronting when conducting this project of HIV/AIDs.

Theme 6: CBPR has its Benefits and Challenges

As discussed in the review of literature, there are many advantages when conducting a study utilizing the CBPR approach. CBPR enhances the use of the research data for all partners involved; it connects partners with different skills and knowledge in attending to complicated health problems, it includes the local knowledge of the people and has the possibility to connect across cultural differences that may be present among partners (Israel et al., 2001). CBPR also has the ability to build upon social capital which promotes connections, social support, and social cohesion, among existing networks and associations in the community (Gilles, 1998; Putnam, 1993).

When interviewing the participants, they described many of these benefits and associated it with the project of HIV/AIDs. They expressed that one of the benefits of utilizing this type of approach was that it would help the community to achieve a "healthier" life style and it could possibly lead to saving the lives of a future generation of H/Ls from contracting this disease. They believed this because of the way CBPR is delivered. One of the participants explained resolutely: "I don't think any community would not benefit with this approach, just in the way it is delivered…good to educate your community so that they could have healthier lives and be informed about diseases that could ruin a future generation…" Without hesitation all of the participants stated that they benefited from the equal treatment they had been receiving from participating and being involved with this type approach. They also commented that community members would also benefit from equal treatment: "…we all have a moral compass to help someone, treat them as an equal; it can happen with this type of research."

Many of the participants spoke very favorably of the benefit of how CBPR builds upon community capacity, and how it assisted them in directing community members to the correct resources. Participants witnessed daily the dire need to access specific resources to assist community members with their many problems of healthcare, substance abuse, and mental illness. The following statement from a participant was a testimonial to this:

> They [community] need support from the different agencies. A lot of people don't know of these programs. My wife has a friend, her son has a drug problem. She called us and asked what she could do. Before I got involved in this program, I didn't really know, this has been most beneficial for me to be involved with the different agencies and now I can help other people.

The majority of the participants were outreach workers who were employed by local agencies in the community. They provided various services in addition to HIV/AIDs testing. These participants personally noticed that another benefit was a decline in the duplication of HIV testing for community members. They attributed this to being involved with CBPR. The participants stated that they were consulting with one another much more and as a result they were able to pass on to one another the information of community members whom had already received the HIV test. In an individual interview a participant enthusiastically expressed: "We need to work on not duplicating services…HIV testing is huge, a test that a lot of agencies offer, say I'm doing and HIV test…and the person has back pain, I refer to the community health center for back pain…"

The participants also came to the conclusion that another benefit of using this type of approach in relation to the project was that it would have sustainability, and it could be used

in other communities in the U. S. as well as globally. The community leader expounded upon these concepts and optimistically expressed: "I see it being sustainable because there are ways to measure…I could see this intervention being done as a peer to peer kind of thing…Start with our community then take it out to the whole state and then globally."

All of the participants were concerned with two specific challenges to utilizing the CBPR approach with the project; one, that it was time-consuming; and two, it would be difficult discussing HIV/AIDs with the children because of the parents' cultural value system. One participant shared: "We can get it done quicker but it is a challenge because of the fact, you know, we have lives that we're living, we have work which is similar to what we're asked to do in this intervention." Along a similar line, another participant stated: "Well, right now, ninety percent of the time, it is a problem with scheduling everyone together, that's rough, and it is a lot of time to get people together." Then the community leader spoke empathically to the group concerning the challenge of time, and expressed the significance of making the time: "…if we could work out the schedule right, if we could stay committed. We had a little test run a couple years ago and I lived in that community and I didn't even know what I noticed when I actually put this approach to work."

All of the participants agreed that a second challenge would be discussing HIV/AIDs with the children. One of the participants realistically expressed: "There is going to be a small percentage, like one percent of people, who completely disagree with our mission, and we will come across some resistance, most likely with the parents. People still have their own set of values…" Another participant echoed in a broader sense:

> The parents, is a big problem with this type of approach, because there are certain parents who want to teach them [children] certain things, and that's the way they want it, and what they teach them is not right.

Discussion

The purpose of this study was to gain an understanding of the experience of H/L community leaders and members with CBPR. Critical social theory and phenomenology were utilized to support the objectives of CBPR and to better understand health disparities with the H/L population. Phenomenology aimed at explaining meanings of CBPR as the participants lived it in their every day life. Critical social theory concerned itself with a problem or practical issue identified by the community through participation, open communication, and critical inquiry and analysis. These approaches assisted in making contributions to the phenomenon of CBPR; specifically, the importance of conducting a community assessment, participants working independently from their agencies on a health problem of concern to the community, the significance of identifying each subculture to the participants, the participants revealing the value of having a researcher engaged and providing structure for the community's project, and a decrease in the duplication of HIV/AIDs testing as a result of being involved with CBPR.

Numerous studies of CBPR have reported that community members involved with CBPR including participants in this study, would be positively impacted by the CBPR process in various ways (Israel et al., 2001; Kelly, 2005; Martinez, 2009; Postma, 2008; Rhodes et al., 2006; van der Velde, Williamson, & Oglivie, 2009; Vissman et al., 2009). It was expected that community members would gain knowledge and research skills that could enhance present employment and/or provide better employment opportunities for the future. CBPR allows an individual and community voice, assists in directing community members to the correct resources, and provides them the opportunity to identify a health need that is of concern to the community. CBPR supports a co-learning capacity-building environment

where the participants can have equal control over a project. It also provides an opportunity for community members to share culturally relevant health data with researchers which can encourage positive health outcomes, and help establish policy change for communities (Israel et al., 2001; Kelly, 2005; Martinez, 2009; Postma, 2008; Rhodes et al., 2006; van der Velde, Williamson, & Oglivie, 2009; Vissman et al., 2009).

Six of the eight participants who participated in this study were employed as outreach workers and the other two participants were outreach workers for their religious organizations. Their function in this H/L community was very similar to the CBPR approach of facilitating in the navigation of the healthcare system, community outreach, health education, and patient advocacy (Farquhar, Wiggins, Michael, et al., 2008; Goodwin & Tobler, 2008; Parker, Israel, Robins, et al., 2008; Silka, Cleghorn, & Grullon, 2008; Vissman et al., 2009). The literature also examined outreach workers collaborating with the their agencies and researchers on an issue that was important to the community (Bent, 2003; Farquhar et al., 2008; Lopez et al., 2007; Meyer et al., 2003; Parker, et al., 2008; Parrado et al., 2005; Rhodes et al., 2006; Vissman et al., 2009); however, this study found that the participants collaborated with each other independently from their agencies. Their reason for working independently was to have more control over the project, and they were proud of the fact that this project was coming from the "bottom up" and not the "top down." As a result, the participants reported being empowered.

The sense of empowerment stemmed from the participants' experience of this study and the fact that the project was being developed by them and not their employment agencies. The participants projected that they could aid the community in operationalizing positive health outcomes and prevention with this intervention of HIV/AIDs targeting the pre-adolescents in the community, and as a result, a sense of hope could be restored (Freire, 1992) in the community (Freire, 1993; Kendall, 1998; Wallerstein, 2002; Wallerstein & Bernstein, 1988). van der Velde et al. (2009) study suggested that obtaining knowledge and empowerment were the motivation for maintaining participation.

It was also reported in the literature how important it was for participants to be involved in the research process of a project and to have learned research skills as it encouraged possible employment opportunities, funding, and research training (Flaskerud & Anderson, 1999; Israel et al., 2001; Kelly, 2005; Rhodes, Hergenrather, Montano, et al., 2006). Martinez et al. (2009) conveyed that one of the benefits for community members was the understanding of the research process. However, not reported in past studies was the participants' perception of having a researcher who was engaged in the community with them. The participants in this study openly discussed the importance of having a researcher who acted as a mentor as well as helping them with structure and direction for the community's project of HIV/AIDs.

More and more researchers are recognizing that H/L people are a heterogeneous group of people composed of individuals from various countries with differing levels of acculturation, education, income, and citizenship status (Balcazar et al., 1991); and, that subcultures are known to have different values, norms, and approaches to living than the dominant culture (Leininger & McFarland, 2002). CBPR generally utilizes community members who reflect the community so that communication and survey questions can be more effective in revealing diverse cultures' understanding of health. The above finding was exemplified in many studies of CBPR. One example, in Meyer's et al. (2003) study of Hispanic LHP/PR, participants shared the choosing of Spanish words instead of English words to design instruments which assisted in reflecting the community's understanding of health. However, participants did not communicate the significance of generalizing all H/Ls into on group, unlike this study, where participants strongly believed that acknowledging this

would help them to better understand the subtle differences of other subcultures that make up this H/L community. Participants did not want to unintentionally insult or offend anyone.

Use of a community assessment has been documented in the literature as one of the initial steps of a CBPR project. Community assessments provide information about the community such as the prevalence of a health problem and environmental factors that affect health. A community assessment is conducted by a researcher, graduate students and/or community members (Kelly, 2005). In this study, this researcher had the participants conduct a complete community assessment. In conducting the community assessment, participants were matched based upon their working relationship in the community. For example, outreach workers were paired together, such as a Pastor being paired with a volunteer HIV/AIDs peer educator/pastoral counselor. The participants were assigned to collect demographics of their target population from local, state, and national statistics of HIV/AIDs, and to conduct community mapping. Community mapping involved going out "on foot" into the community to answer specific questions regarding the neighborhood utilizing an observation report form to help accomplish the task. Several benefits that participants found were that it provided them with a deeper understanding of the community they lived and/or worked in, and it provided them with some working tools so that they could independently conduct future community assessments.

The literature also conveyed that CBPR has the capacity to build upon social capital. Social capital promotes connections, social support, and social cohesion, among existing networks and associations in the community. This reciprocal action has people build up communities and commit to each other (Gillies, 1998; Putnam, 1993). This was demonstrated in a CBPR study by Farquhar et al. (2005), where a project developed from existent social capital of Latino/African communities. Community health workers linked both of these communities to achieve increased access to social and economic resources as it enhanced social capital. This was also illustrated in this study, but in addition to building social capital, it was also found that participants attributed this to being involved with CBPR, as it had them consulting with one another much more, and as a result, they were able to share information regarding duplication of HIV testing among community members.

Limitations/Challenges in Conducting the Study

Challenges in conducting this phenomenological study of CBPR included: maintaining participants in the study, scheduling interviews and instruction of CBPR and CST, inability to conduct a complete CBPR project with the participants, and the writing of the phenomenological text.

Recruiting participants was not a problem because the community leader remained committed to the researcher's study and to the community's project, and he had access to community members he knew were potentially willing to participate in this endeavor. However, retaining the same participants was very difficult. Each time a participant left the group, the researcher had to meet with potential participants several times to gain trust and to explain the project's goal. In retrospect, this led to a "domino effect" of having problems with scheduling interviews and focus groups with the participants. The researcher could have conducted formal interviews as if the participants were applying for a job asking them questions that would reveal if they had the time and the commitment to participate in a research study that involved a CBPR project and their experience with it.

Another problem experienced was related to attendance. The researcher had arranged a time that was convenient for the participants to be interviewed individually and collectively as a focus group, sent e-mail reminders, and called them personally. Some participants did not attend and would only explain that they thought the meeting was at another time. These

actions by the participants sometimes did not match their verbal statements expressing their intention to scheduled interviews and focus groups. Despite the constant reminders and candid conversations, some of the participants would only say that they forgot, or would not even respond. In the literature there is substantial data that many Latin American cultures stress the importance of social acceptance, harmony, and social support, as these cultural values are a focal point to the concept of simpatìa (Holloway, Waldrip, & Ickes, 2009). Simpatìa is a "highly valued relational style" that is based on "the search for social harmony" (Sanchez-Burks, Nisbett, & Ibarra, 2000). When considering this information, it made sense that in the attitude of simpatìa, the participants did not want to tell the researcher that they needed to change their appointment because they did not want to create any immediate disharmony with the researcher.

Another problem involved participants who did not attend the CBPR and CST instructional focus group, and consequently, had to be taught individually. This compromised the CST process as these participants did not initially learn in a focus group format as designed. One of the fundamental processes of CST is to initiate a process of knowing and learning with peers (Freire, 1993). The initial focus group consisted of three participants. This focus group was supposed to educate the eight participants with CBPR and CST. The community leader was previously educated in CBPR and CST. He provided the participants who attended with the example of being a co-educator with the researcher and was able to articulate and share his knowledge of these frameworks with the new participants. The absent participants were not able to truly experience this framework in action and reap the full benefits of it.

Other limitations of this study were: not being able to conduct a complete CBPR project with the participants, and the writing of the phenomenological text. The inability to conduct a complete CBPR project with the participants may have restricted the participants to fully express their lived experience with CBPR. This limitation was unavoidable because a CBPR project requires at least two to five years, and if a researcher receives a grant from the National Center on Minority Health and Health Disparities (NCMHD), a project can take up to eleven years. The NCMHD began the CBPR Initiative in 2005. The initiative is implemented in three phases: three-year planning phase, five-year intervention research phase, and three-year research dissemination (NCMHD, 2005). There was an understanding between the researcher and the participants that the researcher would consult with them until the project was finished.

The writing of the phenomenological text was difficult in the sense of connecting the two projects, that of the researcher studying the lived experience of community members and leader with CBPR, and the participants' HIV/AIDs project. The researcher approached it as one story but with different sub-plots, and had to maintain a consistent mindfulness of keeping it separate but integrated at the same time.

Future Research

A criticism often discussed in the literature is that it is difficult to determine whether or not the CBPR approach contributes to positive health outcomes compared to non-participatory approaches (Agency for HealthCare Research and Quality (AHRQ), 2004; Lee, 2007). In 2003 the AHRQ conducted a meta-analysis of CBPR studies. It revealed that only some studies published outcome evaluation data. For example, several authors mentioned positive effects of their CBPR approaches on research quality and participation rates but did not specify whether or not these benefits improved health outcomes. Later, Lee (2007) took on the initiative to conduct an extension of the AHQR report from March 3, 2003 until March

2006. It also concluded that it was still difficult to determine if CBPR projects generated health outcomes.

In order to more fully explore the phenomenon of CBPR and its projected effects of positive health outcomes, CBPR researchers should conduct longitudinal studies with their interventions; doing so would add to the body of knowledge in identifying if these interventions actually produced positive health outcomes. The participants also agreed with this recommendation and plan to track the children over time (up to the age of 18 or 21) as this would determine if the intervention would be effective in decreasing the prevalence of HIV/AIDs in the H/L community.

Nursing Research Implications for Practice

The use of van Manen's (1990) hermeneutic phenomenology and Freire's (1993) critical social theory frameworks assisted in the understanding of the experience of community leader and members with CBPR. This in-depth understanding could impact future research by supporting nurse researchers to engage and collaborate with community members and leaders utilizing the CBPR approach so that culturally sensitive interventions could be created to encourage health-seeking behavior by underserved communities.

Nurse researchers who utilize these types of frameworks with the CBPR approach will be better able to inform clinical practice about the facts of communities who are experiencing inequities in health, and as a result, healthcare providers will be more attuned to the cultural needs of a community. For example, the participants in this study shared their experience of underlying social oppression in the decision-making process regarding their health, politics, and education. They also expressed that it was crucial for them to recognize that not all H/Ls are the same and that H/Ls come from different subcultures. Being aware of this provided the participants with the insight to construct subculturally sensitive focus group questions that would not offend the various subcultures in the community. Some healthcare providers are not aware of the silent social oppression that exists with the H/L people, and the importance of their not being generalized as a culture. This information can be an impetus for healthcare professionals, not only to practice culturally competent care, but to practice with cultural humility and safety.

Cultural humility, and its relation to cultural diversity, entails a lifetime commitment from healthcare professionals to self-evaluate and self-critique, and to build and sustain equal courteous purposeful partnerships with communities and patients. It also includes recognizing and exploring one's own patterns of unintentional and intentional racism and classism (Tervalon & Murray-Garcia, 1998; as cited in Israel, Eng, Schulz, & Parker, 2005). Cultural safety, gives community members power to say if they feel safe in expressing their worldview to the healthcare professional (Ramsden, 1997). Culturally unsafe practices are seen as "any actions that diminish, demean or disempower the cultural identity and well being of an individual" (National Aboriginal Health Organization, 2006).

Another implication for nurse researchers is to assist outreach workers or community health workers who want to influence their community programs with their own proposed ideas, using the CBPR approach. This was demonstrated by the participants in this study. The participants were concerned that the agencies they were employed by, continued to educate teenagers and adults about HIV/AIDs; however, evidence from both personal experience of administering HIV testing and the statistical information gathered about the community, still showed persistent increase in HIV/AIDs. They believed that using the CBPR approach and targeting pre-adolescents would be much more effective in decreasing HIV/AIDs in the

community. An additional step to this implication, and to such projects, would be to present the findings collaboratively to community organizations such as hospitals and other local agencies. Sharing this information can help address problems sooner and more effectively.

In conclusion, this hermeneutic phenomenological inquiry in combination with CST has brought to light the experience of community members and leader with CBPR. This study has also reinforced that community members want to participate and be involved with researchers using the CBPR approach in solving health disparities among their people. There is also a need for more nurse researchers to conduct research with underserved communities and to acknowledge that both worlds can come together in solving health disparities. Freire (1993) spoke of how such a cultural synthesis creates better outcomes:

> It is possible to resolve the contradiction between the world views of the leaders and that of the people, to the enrichment of both. Cultural synthesis does not deny the differences between two views; indeed, it is based on these differences. It does not deny the invasion of one by the other, but affirms the undeniable support each gives to the other. (p. 181)

References

Addressing Racial and Ethnic Disparities in Health Care. (2007). Fact Sheet. Retrieved from http://www.ahrq.gov/research/disparit.htm

Agency for Health Research and Quality. (2004). Community-based participatory research assessing the evidence, AHRQ Publication No. 04-E02202. Retrieved from http://www.ahrq.gov

Amendola, M. G. (2005). Perceived health needs of Hispanic/Latino families, Unpublished Manuscript, Department of Nursing, University of Connecticut, CT.

Angeles, J., & Somers, A. (2007). *From policy to action: Addressing racial and ethnic disparities at the ground-level*. Center for Health Care Strategies, Inc. Issue Brief.

Balcazar, H., Aoyama, C., & Cai, X. (1991). Interpretive views on Hispanic perinatal problems of low birth weight and prenatal care. *Public Health Reports, 106*(4), 420-426.

Bent, K. N. (2003). "The people know what they want": An empowerment process of Sustainable, ecological community health. *Advances in Nursing Sciences, 26*(3) 215-216.

Bryant, T., Raphael, D., & Travers, R. (2007). Identifying and strengthening the structural roots of urban health in Canada: Participatory policy research and the urban health agenda. *Promotion & Education, 16*(1), 6-11.

Census Bureau. (2003). U.S. Census Bureau. Retrieved from http://www.census.gov

Census Bureau. (2005). U.S. Census Bureau. Retrieved from http://www.census.gov

Census Bureau. (2010). U.S. Census Bureau. Retrieved from http://factfinder.census.gov

Centers for Disease Control & Prevention. (2002). HIV/AIDs among Hispanics in the U. S. Retrieved from http://www.cdc.gov/hiv/pubs/facts/hispanic/htm

Dallas, C. (2004). How scholarly nursing literature addresses health disparities for racial/ethnic minority men. *The ABNF Journal*, pp. 10-14.

Fact Sheet Hispanic/Latino (English). (2009). Retrieved from http://nih.gov/files/FactSheet_Hispanic_Latino.pdf

Farquhar, S., A., Michael, Y. L., & Wiggins, N. (2005). Building on leadership and social capital to create change in 2 urban communities. *American Journal of Public Health, 95*(4), 596-601.

Farquhar, S. A., Wiggins, N., Michael, Y. L., Luhr, G., Jordan J., & Lopez, A. (2008). Sitting in different chairs: Roles of the community health workers in the poder salude/power for health project. *Education for Health, 21*(2), 1-8.

Flaskerud, J., & Anderson, N. (1999). Disseminating the results of participant-focused research. *Journal of Transcultural Nursing, 10*(4), 340-349.

Flaskerud, J. H., Lesser, J., & Dixon, E. (2002). Health disparities among vulnerable population: Evolution of knowledge over five decades in nursing research *Nursing Research, 51*(2), 74-85.

Foster, J., & Stanket, K. (2007). Cross-cultural considerations in the conduct of community-based participatory research. *Family Community Health, 30*(1), 42-49.

Freire, P. (1992). *Friere pedagogy of hope*. London: Continuum.

Freire, P. (1993). *Pedagogy of the oppressed* (3rd ed.). New York, NY: Continuum International.

Gillies, P. (1998). The effectiveness of alliances and partnerships for health promotion. *Health Promotion International, 13*, 1-21.

Goodwin, K., & Tobler, L. (2008). *Community health workers expanding the scope of the health care delivery system*. Washington, DC: National Conference of State Legislatures.

Heidegger, M. (1962). *Being and time*. New York, NY: Harper & Row.

Hispanic/Latino Fact Sheet. (2009). http://www.ced.gov/hiv/latinos/index.htm

Holloway, R., A., Waldrip, A., M., & Ickes, W. (2009). Evidence that a simpático self-schema accounts for differences in the self-concepts and social behavior of Latinos versus whites (and Blacks). *Journal of Personality and Social Psychology, 96*(5), 1012-1028.

Houghton Miffin Company. (2009). *The American heritage of the English language* (4th ed.). Boston, MA: Author.

Human Resources and Services Administration. (2004). Criteria for designating medically underserved populations. Retrieved from http://bhpr.hrsa.gov/shortage/index.html

Husserl, E. (1970). *The idea of phenomenology*. The Hague, The Netherlands: Nijhoff

Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng., A. J. Schulz, & E. A. Parker (Eds.), *Methods in community-based participatory Research for health* (pp. 3-26). San Francisco, CA: Jossey-Bass.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B. (1998). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health, 14*(2), 182-197.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B. (2001). Review of community-based research. Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19*, 173-202.

Kelly, P. J. (2005). Practical suggestions for community interventions using participatory action research. *Public Health Nursing, 22*(1), 65-73.

Kendall, S. (1998). *Health and empowerment: Research and practice*. London: Arnold.

Lee, J. (2007). *An examination of the effectiveness of community-based participatory research projects in producing intended health outcomes* (Unpublished doctoral dissertation). University of Rhode Island, RI.

Leininger, M. (1994). Quality of life from transcultural nursing perspective. *Nursing Science Quarterly, 7*(1), 22-28.

Leininger, M., & McFarland, M. (2002). *Transcultural nursing concepts, theories, research, and practice* (3rd ed.). New York: McGraw-Hill.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Lopez, E., Lichtenstein, R., Lewis, A., Banaszak-Holl, J., Lewis, C., Johnson, P., Riley, S., & Baum, N. (2007). Drawing from Freirian empowerment methods to develop and use Innovative learning maps: Increasing enrollment of uninsured children on Detroit's Eastside. *Health Promotion Practice, 8*(2), 181-191.

Martinez, I., L., & Carter-Pokras, O. (2009). Assessing health concerns and barriers in a heterogeneous Latino community. Journal of Health Care for the Poor and *Underserved, 17*, 899-909.

May, K., Mendelson, C., & Ferketich, S. (1995). Community empowerment in rural healthcare. *Public Health Nursing, 12*(1), 25-30.

Meyer, M., Torres, S., Cermano, N., MacLean, L., & Monzon, R. (2003). Immigrant women implementing participatory research in health promotion. *Western Journal of Nursing Research, 25*(7), 815-834.

National Aboriginal Health Organization. (2006). Fact sheet: Cultural safety. Retrieved from http://www.naho.ca/english/documents/culturalsafetyfactsheet.pdf

National Center on Minority Health Disparities. (2005). NCMHD Community-Based Participatory Research Initiative. Bethesda, MD: Retrieved from http://ncmhd.nih.gov/our_programs/CommunityParticipationResearch.asp?

Parrado, E., McQuiston, C., & Flippen, C. (2005). Participatory survey research, integrating community collaboration and quantitative methods for the study of gender and HIV risks among Hispanic migrants. *Sociological Methods & Research, 34*(2), 204-239.

Parker, E., A., Israel, B., A., Robins, T., G., Mentz, G., Lin, X., Brakefield-Caldwell, W. et al. (2008). Evaluation of community action against asthma: A community health worker intervention to improve children's asthma-related health by reducing household environmental triggers for asthma. *Health Education & Behavior, 35*(3), 376-395.

Postma, J. (2008). Elucidating empowerment in el proyecto bienestar (the well-being project). *Journal of Advanced Nursing, 62*(4), 441-450.

Putnam, R. (1993). Making democracy work. Princeton, NJ: Princeton University Press.

Ramsden, I. (1997). Cultural safety: Implementing the concept: The social force nursing midwifery. In M. P. T. Whaiti, M. McCarthy, & A. Durie (Eds.), *Mai I Rangiatea* (pp. 113-125). Aukland, New Zealand: Auckland University Press, Bridget Williams Books.

Reason, P., & Bradbury, H. (2006). Handbook of action research. London: Sage.

Rhodes, S., Eng, E., Hergenrather, K., Remnitz, I., Arceo, R., Montaño, J., & Alegria-Ortega, J. (2007). Exploring Men's HIV risk using community-based participatory research, *American Journal of Health Behavior, 31*(2), 146-158.

Sanchez-Burks, J., Nisbett, R. E., & Ybarra, O. (2000). Cultural styles, relationships schemas, and prejudice against out-groups. *Journal of Personality and Social Psychology, 79*, 174-189.

Silka, L., Cleghorn, G., Grullon, M., & Tellez, T. (2008). Creating community-based participatory research in diverse community: A case study. *Journal of Empirical Research on Human Research Ethics, 4*, 5-16.

van der Velde, J., Williamson, D., L., & Oglivie, L., D. (2009). Participatory action research: Practical strategies for actively engaging and maintaining participation in immigrant and refugee communities. *Qualitative Health Research, 19*(9), 1293-1302.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York, NY: SUNY Press.

Vissman, A., T., Eng, E., Aronson, R., E., Bloom, F., R., Leichlter, J., S., Montaño, J., & Rhodes S. (2009). What do men who serve as lay health advisers really do?: Immigrant Latino men share their experiences as navegantes to prevent HIV. *AIDS Education and Prevention, 21*(3), 220-232.

Wallerstein, N. (2002). Empowerment to reduce health disparities. *Scandinavian Journal of Public Health, 30*(59), 72-77.

Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education Behavior, 15*(4), 379-394.

Wallerstein, N., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*(3), 312-326.

Author Note

Mary Grace Amendola, PhD, RN is assistant professor at Rutgers College of Nursing, Rutgers University, Newark, New Jersey.

Correspondence concerning this article should be addressed to Mary Grace Amendola, Rutgers College of Nursing, Rutgers University, Newark, NJ, 07102 E-mail: mariegraceus@yahoo.com

Article Citation