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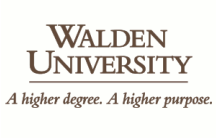

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Walden University

College of Health Sciences

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Ivonne G. Kanko

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Walden University
2017

Abstract

Perceptions of Community-Based Participatory Research from Community and Academic Members

by

Ivonne G. Kanko

MPH, MBA, Saint Xavier University, 2008

BA, University of Yaounde I, 1998

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

February 2017

Abstract

Community-based participatory research (CBPR) is an increasingly popular form of public health research. However, little is known about the application of CBPR and the levels of involvement for partners in specific phases of the partnership. This phenomenological study addressed the application of CBPR from the perspectives of 7 academic researchers and 6 community members experienced in CBPR. Arnstein's ladder of citizenship participation and the community coalition action theory provided the framework for the study. Semi-structured interviews addressed participants' levels of involvement in the CBPR process, as well as challenges, concerns, successes, and recommendations for improvement. Interview transcripts were analyzed by identifying recurrent themes relevant to the experience of being a CBPR partner. These themes were then used to develop descriptions of their experience. Results indicated that participants knew the term CBPR and had experienced it, but not all participants understood the depth of CBPR and how much bargaining power they could have for their community. Sustainability of partnerships and programs was a major concern. Ethical problems were also raised regarding the long-term commitment to projects and the need for CBPR partnership evaluation. Results may be used to strengthen awareness of the principles of CBPR to advance culturally tailored public health interventions.

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Chapter 1: Introduction to the Study

I conducted a phenomenological study of an increasingly popular approach to public health practice known as community-based participatory research (CBPR) (Holden et al., 2016; McShane, Usher, Tandon & Steel, 2015; Medeossi, Standler, & Delany-Moretlew, 2014; Salimi et al., 2012). CBPR is an approach to research that requires equitable benefit and involvement of all partners in all phases of the research, drawing from the strength of the researcher and the community involved with explicit focus on social change for the participating community (Goodyear-Smith, Corter, & Suh, 2016; Israel, Schulz, Parker, & Becker,1998; Rhodes, Malow, & Jolly, 2010). *Community* has been defined by experts as a population of individuals emotionally connected, with a common sense of identification and shared norms and values, common interests, and commitment to finding solutions to their common needs (Atalay, 2012; Community Campus Partnership for Health [CCPH], 2013c). This form of research is based on the idea that the involvement of concerned community partners in the planning and implementation of community-relevant research and interventions ensures locally informed and culturally appropriate public health research and interventions, and it also helps with adaptation and fidelity of intervention (Castro, Barrera, & Holleran Steiker, 2010).

Due to the promise of productive and culturally appropriate health promotion planning and implementation, there has been continuously growing demand by research funding agencies for researchers to involve the communities they target as pivotal partners in their research activities (Nyden, 2003b). The use of CBPR is evident in

planning of many health promotion programs (Jardin & James, 2012; Redman-MacLaren et al., 2012; Schwab, 1997; Simonds, Wallerstein, Duran, & Villegas, 2013), and elements of CBPR appear to have taken root in health care organizations in the United States in the form of patient-centered outcome research (Clancy & Collins, 2010; Selker, Frist, & Altman, 2013). All these efforts are designed to reduce the prevalence of disease and the high cost of health care in the United States (Organization for Economic Co-operation and Development [OECD], 2013). Culturally tailored public health intervention programs as a result of CBPR partnerships could account for effective use of scarce funding for public health-related issues (Pizzi et al., 2014).

As a result of the increased requirements by funding agencies for grantees to use CBPR, there has been an increase in the number of researchers who claim to conduct research following the principles of CBPR (Jagosh et al., 2011). Although many researchers have reported the apparent success of CBPR in health promotion and disease prevention (Davis et al., 2012; Jardin & James, 2012; Redman-MacLaren et al., 2012; Sadler et al., 2012), little has been done to evaluate the application of CBPR and the levels of involvement for partners in specific phases of the partnership and projects.

Although there are no universally accepted characteristics of what constitutes CBPR, Israel et al. (1998) developed a set of guiding principles that are cited by CBPR researchers with increasing frequency. In this study, they are referred to as the *guiding principles* of CBPR:

- looks at the community as a unit of identity and partnership,
- builds on the community's strengths and resources,

- enables partners' involvement equitably in all aspects of the research,
- integrates inputs of all partners for their mutual benefit,
- promotes empowerment through colearning process that address health and social inequities,
- involves a continuous and sustainable research process,
- addresses health from both ecological and positive perspectives,
- shares findings and acquired knowledge with all stakeholders, and
- encourages long-term partnership commitment.

Although not every one of these characteristics may be applied all the time, CBPR is the equitable involvement of researchers and community members in partnership in all stages of the study, with focus on finding solutions to issues concerning the partnering community (Green & Mercer, 2001; Jagosh et al., 2015; Minkler & Wallerstein, 2008). The promise of CBPR is to build trust that mutually benefits all stakeholders (Schulz, Israel, Selig, Bayer, & Griffin, 1997) and lasts through and beyond the study. CBPR is also used to build and strengthen the community's research capacity by involving community members at the onset of research planning, especially when determining research questions and designing the study through evaluation, dissemination of findings, and authorship. Skillfully implemented, CBPR can be used to enhance sustainability in the research process, advocate for the community's needs, honor and respect all stakeholders while protecting their interests, disseminate findings, create awareness, consider needed and available resources in the community, and ensure equitable

recognition for the work done (Anderson et al., 2012; Hicks et al., 2012; Kamanda et al., 2013).

In practice, however, these lofty ideals may not be met. Community partners are often more likely to be less experienced in research than their academic partners and more vulnerable in terms of exposure to risk (Brown et al., 2010; DiStefano et al., 2013). Although there have been CBPR success stories, critical issues remain, especially with regard to researcher treatment of marginalized and vulnerable population community partners. Stacciarini, Shattell, Coady, and Wiens (2010) reviewed multiple reports of studies of mental health in minority populations that claimed to have used CBPR and found that less than half (20 out of 50) met even some of the criteria for CBPR. In another study of partnership research involving Canadian Aboriginal community members and mainstream academic researchers, Schinke, Enosse, Pelter and Watson (2010) found that the community participants were routinely silenced throughout the research planning process, and cultural research practices were unfamiliar and meaningless to them. The researchers and community partners later agreed on culturally appropriate research methods for collaborative research with marginalized groups. In DiStefano et al.'s study (2013), ethical tension occurred as community-based organization partners felt pressured by academic partners as they pushed their research agenda, and almost risked recommending less research rigor. These findings warrant more investigation into the CBPR approach, including proper ethical protections, especially for minority community partners, and communities as partners in the research (Casado, 2013; Cross, Pickering, & Hickey, 2014; Shore et al., 2015).

Evaluation of public health research and interventions is critical in determining the community's relevance in intervention priorities and ensuring appropriate and productive use of funds. Public health evaluation may in some cases prompt positive policy changes to benefit the community involved as well as general population health (Ritas, 2003; Viswanathan et al., 2004). Failure to conduct this kind of evaluation could hinder future research projects in communities experiencing the greatest public health disparities. Research participants in the community should enjoy the complete benefits of participation in research. This fosters trust and promotes partnership sustainability and continuity in research and other ventures (Israel et al., 1998; Morgan et al., 2014; Jagosh et al., 2015).

Background of the Problem

The literature on CBPR has showcased success stories (Anderson et al., 2012; Flicker, Travers, Guta, McDonald, & Meagher, 2007; Israel et al., 1998; Schwab, 1997; Simonds et al., 2013; Townsend et al., 2016; Unertl et al., 2016; Viswanathan et al., 2004), and there is some evidence that CBPR could be an effective way to design and conduct valuable, useful, and empowering social change programs that promote health (Davis et al., 2012; Jardin & James, 2012; Redman-MacLaren et al., 2012; Sadler et al., 2012). However, there remain some noticeable challenges to this research approach (Anderson et al., 2012; Nöstlinger & Loos, 2016; Riffin et al., 2016). These challenges include diverse institutional goals, poor communication, different perspectives in formal processes such as grant applications and reports, and community members' frustration with the inevitable delay in intervention results (Anderson et al., 2012; Mason et al.,

2013). Although efforts are being made by academic partners for research capacity building, community partners remain less likely to be experienced in and to master the art of research, and may be vulnerable to unfamiliar research practices (Nyden, 2003a). Community partners in most cases are from low-income populations and may also have different priorities from academic researchers, who may come into partnership with a research agenda obtained from literature or observation. This may cause lack of project commitment from community partners (Brown et al., 2010; DiStefano et al., 2013; Riffin et al., 2016).

The promise of CPBR is to benefit all stakeholders. At its best, community-based participatory research can do this by building trust that lasts through the study and beyond (Schulz et al., 1997), strengthening research capacity for community partners, advocating for their needs, honoring and respecting all stakeholders, disseminating findings to inform the community, creating awareness, considering needed and available resources for and in the community, and ensuring equitable recognition for the work done (Anderson et al., 2012; Hicks et al., 2012). Other entities and researchers including Community Campus Partnership for Health and Community Tool Box have made efforts to provide educational online resources to CBPR and other community-engaged partners to learn about the process of partnership governance and implementation (CCPH, 2016; Communty Tool Box, 2016). However, evaluation of authentic CBPR partnership has not been addressed by researchers, and there is no standard framework for evaluating CBPR partnerships and processes.

Purpose of the Study

Using the CBPR's guiding principles (Israel et al., 2003), Arnstein's (1969) ladder of citizen participation, and the community action coalition theory (Butterfoss & Kegler, 2002), I explored the perspectives of community and academic CBPR partners regarding the application of CBPR's guiding principles, the different levels of involvement using Arnstein's degrees of participation in their CBPR partnerships, the challenges they have experienced, and recommendations for best practices. I also examined the extent to which academic research institutions through their ethics committees or institutional review boards (IRBs) ensure that they are protecting not only the interests of research participants but also those of the communities to which these research participants belong. This is especially relevant in cases when a single individual, such as a pastor, represents an entire community on a research project. I also examined participants' perceptions of the three unexplored challenges among academic researchers and community participants in CBPR projects in selected low-income African American and Hispanic neighborhoods in a major metropolitan area.

Scope of the Study

I examined the lived experiences of academic researchers and community members in CBPR partnerships in an urban city. I examined the authentic use of the CBPR guiding principles, levels of involvement in the partnerships, benefits, outcomes, unexplored challenges, success factors, and recommendations for CBPR best practices through lessons learned.

Research Questions

The following three research questions were used to guide the study:

Research Question 1: What are the perceptions of academic researchers and low-income community members about their experience of the process of CBPR before, during, and after their partnership?

Research Question 2: What are the levels of participation experienced by participants at each stage in the research process?

Research Question 3: What challenges, ethical issues, benefits, and outcomes have participants experienced during their CBPR partnership?

Limitations

There might have been unwillingness on the part of community partners to objectively answer questions relating to challenges faced with academic research partners with whom they had established a social and professional relationship. Intimidation or fear of losing their partnership might have been a concern. To counter this concern, I reminded participants that their identities and agency information were de-identified. Moreover, community participants might not have been properly informed about the CBPR guiding principles, and they might have required some form of information and education about the CBPR requirements and expectations. In these cases, I briefly explained the principles prior to the interviews. This was a qualitative study, and results are not generalizable although they may indicate commonalities with other projects or communities. Qualitative in-depth interviews were conducted to gather data on the extent

of adherence to the CPBR guidelines and degrees of participation in the CBPR approach to research.

Significance of the Study

The goal of this study was to advance equitable ownership in public health research and intervention and to promote the strengthening of community leaders' research capacity for sustainability. Findings from the study provide in-depth analysis of the real-life practice of CBPR to educate scholars and the community about potential weaknesses and challenges of CBPR from the perspectives of research faculty and community members who had been exposed to the CBPR approach. This may contribute to policy development regarding IRB ethics and requirements for CBPR projects, and may prompt the adoption of best practices in CBPR within communities and their partnerships with university researchers.

Summary

Community-based participatory research is gaining recognition and emphasis as funders are requesting community-focused research that balances problem-solving in a collaborative context to effect positive social change and social justice. With the already high cost of health care in the United States, public health disease prevention and health promotion are necessary to reduce unnecessary health expenditures. It is therefore justifiable to consider the cost-benefit factors in funding CBPR research projects by establishing as a requirement positive public health outcomes. The authentic practice of CBPR favors the above framework; however, there exist some challenges in the inception, planning, process, and outcomes of the research approach, particularly in the

area of ethics and protection of the minority community as participants and partners working with academic researchers.

A review of relevant literature follows this chapter. Chapter 3 provides a description of the study design, procedures, participants, and assessments. Chapter 4 presents the results of this study, and Chapter 5 includes an interpretation of findings and recommendations for sustainable CBPR practice.

Chapter 2: Literature Review

Community-based participatory research is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings, with the goal to find solutions to identified issues in the partnering community (Israel et al., 1998; Kellogg Foundation, 2016; Riffin et al., 2016). Although many researchers have reported the apparent success of CBPR in promoting health and in preventing diseases, little has been done to evaluate the application of CBPR's guiding principles and the levels of CBPR partnership participation in specific projects.

Literature Search Strategy

I conducted a literature search on CBPR interventions, challenges, and issues using the following key words: *community based participatory research, community based participatory research challenges, community based participatory research ethical issues, community-campus partnership in research*, *CBPR partnerships*, and *CBPR partnerships in Chicago*. I used Google, Google Scholar, PubMed-NCBI, and SAGE search engines, and key words served as a guide to finding publications related to my topic. Publication dates ranged from 1969 to 2016. Key frameworks and theories applied in the study are not recent, and it was important to capture the origin of the theory and guiding principles of CBPR. It was also important to capture the historical perspective of CBPR challenges, successes, and evolution through the years.

Three thousand two hundred and sixteen peer-reviewed sources on CBPR were identified on PubMed, while 760,000 peer-reviewed sources were located using the

Google Scholar search engine. Narrowing the searches to specific CBPR topics reduced the number of articles to 180.

Theories and Conceptual Framework

The community action coalition theory (CACT) (Butterfoss & Kegler, 2002), which has been used to foster community agreement among diverse individuals and organizations in partnership to address community issues, informed this study. The CACT provides a framework for examining the processes of partnership building, shared governance, and the outcomes of CBPR projects. A focal point of the theory is promotion of long-term commitment among partners after a project is executed to ensure continuity, coalition formation and functioning, partnership synergy, and establishment of community and organizational change (Butterfoss & Kegler, 2002).

The CACT model and principles provided a framework for exploring the structures, processes, and results experienced by effective and authentic community coalitions in addressing intermediate and long-term health outcomes. Community partners as well as academic researchers were asked to answer questions relating to the application of CACT principles in conducting CBPR collaborative research, and also to report on various challenges experienced during the research process and partnerships. In addition, I used the guiding principles by Israel et al. (2003) as a framework for evaluating critical elements of community participation in this study. Arnstein's (1969) degree of participation classification was also used to measure the levels of participation in the CBPR projects.

There are degrees of participation, and Arnstein (1969) outlined eight levels as steps on a ladder of citizen engagement. The most authentic participation is called citizen power in which community partners have recognized input in decision-making throughout the research process, and also benefit from the research. A lesser degree of citizen participation is tokenism, which Arnstein defined as situations in which community partners are informed or consulted but have limited input. The use of community partners in therapeutic or manipulative situations is considered nonparticipation. Nonparticipation is characterized by situations in which the community partner is said to benefit from the research but is manipulated and has no control at all (Arnstein, 1969).

Practice of CBPR

With its roots in the social and political movements of the 1940s, 1960s, and 1970s, CBPR is an approach to research that acknowledges input from all community partners. Its evolution drew heavily on the writings of Freire (1970), who emphasized the idea of communities picking out and prioritizing their own issues and solutions. This model has contributed a great deal to the field of public health promotion. The Community Health Scholars Program (2001), which has been funding fellowship programs in CBPR, defined CBPR as

> a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. Community Based Participatory Research begins with a research topic of importance to the

> community and has the aim of combining knowledge with action and achieving social change. (p. 2)

The term *community* in CBPR has been defined as "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (MacQueen et al., 2001, p. 1929). The Community Campus Partnership for Health (2013c) defined community as a group of people characterized by a sense of identification and common emotional connection to other members with shared values and norms, common interests, and commitment to meeting shared needs. The CBPR approach to research includes nine principles as presented by Israel, et al. (1998):

> It (1) recognizes the community as a unit of identity and partnership; (2) builds on strengths and resources within the community; (3) facilitates the collaborative, equitable involvement of all partners in all phases of the research; (4) integrates knowledge and intervention for mutual benefit of all partners; (5) promotes an empowering colearning process that addresses social inequalities; (6) involves a cyclical and iterative process of research; (7) addresses health from both positive and ecological perspectives; (8) disseminates findings and knowledge gained to all partners; and (9) encourages long-term commitment by all partners. (pp. 178-180)

Although not every characteristic may be applied all the time, CBPR is the equitable involvement of researchers and community members in partnership. The

promise of CBPR is to build trust that lasts through the study and beyond (Butterfoss, DiClemente, Crosby, & Kegler, 2002) and that mutually benefits all stakeholders (Centers for Disease Control and Prevention, 2013; Schulz et al., 1997). Community based participatory research is used to build and strengthen the community's research capacity by involving community members from the onset of the research planning (Minkler et al., 2012), especially when determining research questions and designing the study.

CBPR, Community-Based Research (CBR), Community-Placed Research (CPR), and Traditional Research

According to the Community Campus Partnership for Health (CCPH, 2013a), there is a growing recognition that traditional research approaches have not resolved complex health inequities. Community members have been feeling over-researched (CCPH, 2013a) and have increasingly demanded that research address their locally identified needs. CCPH also argued that significant community involvement could lead to scientifically sound research, and findings could be directly applied to formulating culturally appropriate interventions that have the potential to establish greater partnership, trust, and respect (Kiawi, McLellan-Lemal, Mosoko, Chillag, & Raghunathan, 2012).

One of the problems in assessing this view is that research performed in the community is often referred to as a CBPR project. However, when Jagosh et al. (2011) reviewed a series of publications on research studies and projects described as CBPR, they found a significant number failed to have applied an authentic CBPR approach.

Similarly, Stacciarini et al. (2010) found that despite the need for culturally appropriate interventions and research requested by minority communities to address their culturally unique problems related to mental health, most researchers continued to apply the traditional procedures of community placed research (CPR) that did not involve true community participation.

The difference is important. Whereas CBPR researchers works with the community to explore problems and find solutions, CPR researchers works in the community as a place or setting (Israel, Schulz, Parker, & Becker, 2001) without emphasis on shared governance of the research with the community. Full CBPR includes equitable benefit and recognizes all partners as equal stakeholders involved in every phase of the research and partnership (Israel et al., 1998). According to the University of Iowa Human Subject Office (2016), CPR is defined as "research…happening IN the community setting but is still researcher (academic) driven, community members are not active participants" (para. 3). CPR includes members of the community as part of the research but usually only as subjects of the research; it does not involve them in planning and implementation of the research. A form of research similar to CBPR is community based research (CBR), which is done with the community with a limited degree of involvement in certain phases of the research. Here the community and participants have a say in the research, but it is mostly led by academic researchers (University of Iowa Subject Office, 2016). It is important to note that all forms of research described above have different sets of guiding principles and requirements. Whereas CBPR requires all partners to be equitably involved at every stage of the research, the CBR requirements

stress the design of the study and the use of research outcome results (Strand, Marullo, Cutforth, Stoecker, & Donohue, 2003).

CBPR has an added advantage over traditional research and has been a popular form of research due to its emphasis on social change, community empowerment, and quest for community health program sustainability (Gulaid & Kiragu, 2012; Shore et al., 2015). Figure 1 presents a comparison of CBPR and traditional approaches. It emphasizes the community engagement in CBPR as opposed to traditional research, which addresses community members as research subjects.

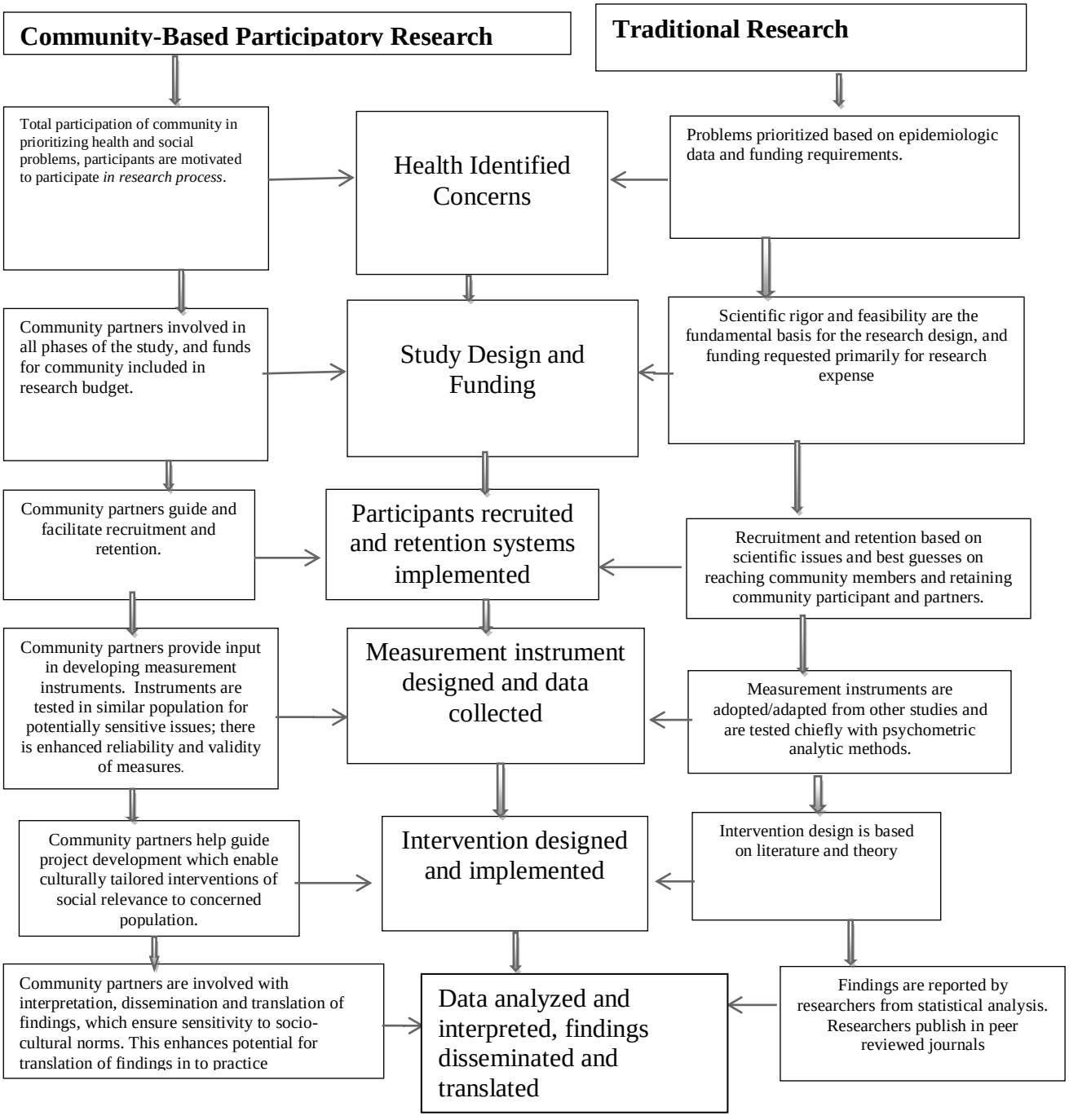

Figure 1. CBPR vs traditional research (University of Washington, 2013)

Ethical Considerations in CBPR

One major concern in CBPR that has not been well explored is the role of the institutional review board (IRB) in universities that use the Belmont guidelines for ethics in biomedical research (National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research [NCPHBBR], 1979; U.S. Department of Health and Human Services, 1998), which were designed to protect human subjects but not communities (Flicker et al., 2007). More effective community protections in CBPR projects have been proposed (Shore et al., 2015) but not widely implemented, especially in minority communities (Jagosh et al., 2011; Stacciarini et al., 2011).

Although initiatives have been put in place to ensure the protection of indigenous, vulnerable research participants (Grignon, Wong, & Seifer, 2008; Navajo Nation IRB, 2003; NCPHBBR, 1979), and research funding agencies such as the Centers for Disease Control and Prevention (CDC) and the National Institutes for Health (NIH) have sponsored ethical committees to ensure protection of the community in the process of research collaboration with academic researchers (DiStefano et al., 2013; Shore et al., 2015), there is still a widespread lack of authentic ethical protection for communities engaged in CBPR research practice (Jagosh et al., 2011; Shore et al., 2015).

Juritzen, Grimen, and Heggen (2011) examined the relevance of institutional and ethical committees and found that claims by institutions to protect research participants and researchers had some loopholes. Schneider (2013) found that bureaucratization in these institutions hindered authenticity and purpose of research. Such problems could hurt research, researchers, vulnerable participants, and the marginalized community as

there may be risk of coerced participation in and administration of the research resulting in invalid research findings.

Benefits of CBPR

The promise of Community Based Participatory Research is to birth public health programs that impact positively majority of people and communities thus building social change (MacQueen et al., 2015; Unertl et al., 2016 p.66). CBPR could help ensure that the problem is properly defined, the solutions are properly defined, the intervention is appropriately and realistically developed, and the outcomes of the intervention are effective in addressing the problem. (Gulaid & Kilagu, 2012). Effective CBPR relationships empower communities to plan and promote their own health (Kamanda et al., 2013). Skillfully used, it can advocate for the community's needs, respect all stakeholders while protecting their interests, take consideration about needed and available resources in the community, ensure equitable recognition and ownership for the work done, and disseminate findings that inform and create community awareness (Hicks et al., 2012; Flicker et al., 2007;). Properly done, it could be beneficial in mapping community health resources, prioritizing health inequity in preparation for public health research and interventions (Shah, Whitman, & Silva, 2006), and inserting sustainability into the research process (Israel et al., 2006; Macauley et al., 2011; Seifer, 2006).

Funding

Funding public health programs and services is primary issue due to competition for resources with other governmental agencies (Meit et al., 2013 p. 44) which raises the importance of proper management of funds making sure that both partners in CBPR

collaboration have access. Decisions must be made about who controls the funds and who gets paid for participation. In true CBPR, joint ownership of a study is established; the costs and benefits of partnership for all partners are determined; roles are defined for each participant for the data collection, analysis, and interpretation; and agreements are made about dissemination and outcome. Decisions are generally established on the financial implications of all these items in a mission statement and a Memorandum of Agreement between the parties (CCPH, 2013a; Israel et al., 1998). Every step of the process is taken into consideration with community partners during the planning phase of the research from identifying health concerns to developing study design, recruitment and retention strategies of participants, designing measurement instrument, data collection, intervention design and implantation, data analysis and interpretation, dissemination of findings, and translation of research findings.

Rationale for CBPR Over Other Research Approaches

Historically there has been Community Based Participatory Research existence (CBPR) in different shades, that engaged or involved communities in research interventions in some aspects to finding urban health and urban issue solutions, until the establishment of the CBPR guiding principles by Israel and colleagues in 1998. The literature on CBPR has showcased some success stories, and there is some evidence that CBPR could be an effective way to design and implement culturally appropriate and empowering social change programs that support health promotion (Davis et al., 2012; Sadler et al., 2013; Schwab et al., 1992; Travers, 1997; Wang & Burris, 1994). In their project developing a wellness guide as a model to better promote health, Schwab (1992)

designed the project with community involvement not only in creating an English language version of the guide but also in preparing a Spanish adaptation, consulting with scholars, community leaders, businesses, and health care workers to create a product that was sensitive to the needs of people of all social and ethnic backgrounds. It became a household product to assist citizens find reliable health information and direction to needed resources (Schwab, 1992). Another Community Based Participatory Research success from a historical perspective told by Wang and Burns (1994) presented a social change study which used a different form of Community Based Participatory Research that involved members of the Yunnan village as photographers in the creation of a form of picture essay like a photo novella. In this study, the intervention covered provision of photo cameras to community members as participants who had experienced social and health inequities, which allowed participants to record their daily lives and their environment in the community; this created an opportunity for them to showcase images of their social, personal, and community issues which consequently were acknowledged by decision makers in their community and evidently enabled community empowerment. According to Wang and Burns (1994), this form of intervention and partnership allowed for community members with limited access to power to exhibit and provide authentic images taken from their own communities.

Community Based Participatory Research success stories in health promotion was seen in Simonds et al. (2013). The authors carried out a national study of community engaged research projects on cancer intervention and prevention, and identified 64 of 333 projects focused on cancer and highlighted some positive impact from participatory

approaches in reducing cancer disparities (Simonds et al., 2013). More projects highlighted the success of participatory approaches to cancer prevention and intervention in addressing some challenges of biomedical research (Simonds et al., 2013). Kamanda and colleagues (2013 p.9) also saw successful outcomes in the use of CBPR when they fully engaged the village chiefs and faith based leaders in refining the study design and identifying research questions that were impacting orphaned and separated non-orphaned Kenyan children, in their CBPR project "The Orphaned and Separated Children's Assessments Related to their Health and Well-Being (OSCAR)" longitudinal 5 year study (Kamanda et al., 2013 p.2) This participatory method helped the authors in recruitment and retention of participants in their study, as the community representatives were empowered and assumed ownership of the recruitment process. The CBPR research approach could therefore also strengthen epidemiological and public health research as emphasized by (Kamanda et al., 2013).

Community-Based Participatory Research can be effective in influencing social change in a community or society. Michalak et al. (2016), in their CBPR study of bipolar disorder (BD), showed that CBPR can be effective to fully engage participants. Applying this approach to research helped the authors find out that participants had concerns about medication treatments. Participants with lived experience of BD reported that current treatment trial designs may not address their core questions, such as "If I don't take medications or want to take a lower dose than is typically recommended, what are my odds of relapse?" (Michalak et al., 2016 p.3) Because participants are well informed about their community and their issues, the CBPR approach to research may foster

seamless intervention as it is appropriately and culturally tailored, thus enabling proper use of already scarce economic and financial resources in public health and healthcare in general (Masau, 2015; Gillespie, 2016).

Effective Community Based Participatory Research could also possess the tendency of affecting change to the mass and larger population compared to traditional forms of intervention that do not consider input from community stakeholders and community members (CCPH, 2013b). Freudenberg & Tsui (2014) also agree that this approach to research could easily stand a chance to affect policy change and adoption of a health issue.

CBPR and Community-Campus Collaboration

Though there are several types of partnership in CBPR, one of the most common is academic-community collaboration. In most cases, faculty in the academic institution initiate the collaboration, either because of the great interest that this approach has excited in academics over the last 20 years with grant funding requirement or because CBPR has become a popular requirement for tenure opportunities (Allen et al., 2010; Allen et al., 2011). A few examples of academic institutions championing community-academic partnerships are: The Detroit Community-Academic Urban Research Centers (Detroit URC) funded by the Centers for Disease Control and prevention (CDC) through their Urban Research Initiative. This partnership is made up of university of Michigan researchers and over 10 community partnering organizations focusing on different social and health issues according to information from their website (Detroit URC, 2015). Some

of their partnership outcomes are showcased in (Cheezum et al., 2013; Kieffer et al., 2013; Izumi et al., 2012; Izumi et al., 2010; Schulz et al., 2015) to name a few.

The Community Campus Partnership for Health (CCPH) is the parent organization of community-campus collaboration for health and research in the United States (CCPH, 2013b). It is recognized locally and globally for advocating and ensuring true community and academic partnerships in research and health. Since its inception in the 1990s, after the first decade of participatory research in public health had shown how these partnerships were possible, the CCPH has developed, assessed and evaluated some collaborative relationships with a view to reducing barriers and challenges in forming and sustaining these partnerships. The CCPH is a non-for-profit organization with the following 12 guiding principles for effective community-campus partnership in CBPR and health (CCPH, 2013d): “

1. The partnership forms to serve a specific purpose and may take on new goals over time.
2. The partnership agrees upon mission, values, goals, measurable outcomes and processes for accountability.
3. The relationship between partners in the partnership is characterized by mutual trust, respect, genuineness, and commitment.
4. The partnership builds upon identified strengths and assets but also works to address needs and increase capacity of all partners.
5. The partnership balances power among partners and enables resources among partners to be shared.

6. Partners make clear and open communication an ongoing priority in the partnership by striving to understand each other's needs and self-interests and by developing a common language.
7. Principles and processes for the partnership are established with the input and agreement of all partners, especially for decision-making and conflict resolution.
8. There is feedback among all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes.
9. Partners share the benefits of the partnership's accomplishments.
10. Partnerships can dissolve, and when they do, there is a need to plan a process for closure.
11. Partnerships consider the nature of the environment within which they exist as a principle of their design, evaluation, and sustainability.
12. The partnership values multiple kinds of knowledge and life experiences"

Campus-Campus-Community Collaboration in Chicago

The city of Chicago and surroundings are budding with collaborative health initiatives involving academia and the local communities. All of them seem to be committed to efforts to increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and injury, improve health, and enhance quality of life, as noted in the Health People 2020 goals (Department of Health and Human Services, 2013; Lindau et al., 2011) and as funding agencies so often require.

The Chicago metropolitan area is known for its diversity in terms of population and social structure (Chipman, Wright, Mark Ellis, & Holloway, 2012). Chicago also has some of the top 25 research universities in the country (Center for Measuring University Performance, 2013 p. 6). Furthermore, Chicago communities mostly affected by low socioeconomic and health outcomes are saturated with churches and community based agencies, which cater to the health, social, and spiritual wellbeing of the community. Researchers in these universities often seek to collaborate with the organizations to gain access to the population and recruit research participants for CBPR projects to promote the health of the community.

In this way, a new breed of collaboration has developed among the universities and faculty from a predominantly black university with trusted access to these impoverished communities, mostly to gain access to the community for research purposes. It is perceived that faculty of this predominantly black higher education institution located in the core of a predominantly black neighborhood will have easier access to the community than faculty from other neighboring universities. However, little had been done to evaluate the value and outcome of such collaborations.

My study examined such partnerships in view of the CBPR guiding principles, the success of the collaboration, possible ethical issues, the degree of participation, and how the different collaborations benefit the community. It is of special interest that with the presence of these community health programs, centers, and research partnerships in Chicago's low-income neighborhoods, there were still reports of deteriorating health and aggravated crime rates of people in these communities, with high rates of such public

health issues as gun violence, teenage pregnancy, HIV/AIDS, obesity, diabetes, and other chronic diseases. These Chicago communities are still ranking top in health disparities and social inequalities in Illinois (Northwestern University, 2011)

Challenges and Barriers in CBPR

Although the literature on Community Based Participatory Research (CBPR) has presented some success stories in health promotion and disease prevention there was also evidence of significant challenges relating to this research approach. Israel et al. (2003) pointed out the following common challenges in the CBPR, project sustainability after funding ends and funding issues, building research capacity for the community partners, and lack of complete shared governance, to name a few. A major challenge that still exists is sustaining partnership and program benefit after funding ends. Hacker et al (2012) in their study to seek definition of Capacity building and sustainability in CBPR, the researchers performed a break out group discussion among academic researchers and community partners at a community-academic conference. The researchers observed that project sustainability depends on fund-raising capacity, which is enhanced when goals are shared from the start of a partnership, and partnership or project goals are being achieved (Hacker et al., 2012 p.6).

Project sustainability after funding and funding issues. When a project is ongoing, one reported challenge is how to compensate the community members and their staff. When a project ends, a big challenge arises in maintaining continuity of the intervention to better effect change of the community and participants. Most of the tasks involved include financial support to cater for required resources, but unfortunately grant

awards are only for a specific period of time and a specific task, and most often, the funds are present long enough to get intended program outcome maintained.

Building research capacity for the community partners. Academic researchers in most CBPR partnerships assume the role of the principal investigators (PIs) and research experts. Lack of training time for the community partners and the pressing study timeline of some research studies could be reasons why academic researchers may not take time to train and empower community partners on how to conduct research. Oftentimes, community partners may leave the research formation, data collection and analysis, and writing for publication in the hands of their academic partners out of lack of personal confidence in the process and possibly feelings of intimidation.

Lack of complete shared governance. Power distribution among partners (Schwab & Syme, 1997) could be a big challenge, ranging from funding to publication, authorship and ownership of data. Oftentimes, academic researchers have control over almost aspect of the research including data and local and national recognition for publications, making it unbalanced as a CBPR partnership. Community partners in this case basically facilitate participant recruitment and data collection especially in cases where members of the community are hard to reach as research participants. In this situation, an ethical issue on protecting community partners also arises (CCPH, 2013; Freeman, Shore et al., 2015; Israel et al., 2013)

Community partners from marginalized populations. Community partners are especially likely to be inexperienced in research dynamics and may be vulnerable to unfamiliar research practice (Brown et al., 2010) which may result in unequitable

partnership and participation. Several authors showcased the benefits of properly following the guiding principles in the practice of CBPR (Israel et al., 2003; Simonds et al., 2013) even to the point of proposing that more community participation could be a solution to the issues of 21st century epidemiology (Schwab & Syme, 1997). These proponents of CBPR pointed out that public health research and interventions in the community have traditionally been instigated by academia or government agencies with little or no community involvement and ownership, and this has limited their relevance and effectiveness (Flicker et al., 2007).

Equitable benefit. Another challenge relates to the benefits of projects created using CBPR. In its purest form, CBPR seeks to impact social change and justice involving all stakeholders equitably in the research, to combine the expertise of all parties, and to ensure mutual benefit and respect (Detroit Community-Academic Urban Research Centre, 2011; Israel et al., 1998). It recognized the forte of each collaborator with some sensitivity on levels of expertise (Schulz et al., 1997).

The promise of CPBR is to mutually benefit all stakeholders. At its best, CBPR can do this, building trust that lasts through the study and beyond (Schulz et al., 1997), strengthening research capacity for community partners, advocating for their needs, honoring and respecting all stakeholders, disseminating findings to inform the community, creating awareness, taking consideration about needed and available resources for and in the community, and ensuring equitable recognition for the work done (Flicker et al., 2007; Hicks et al., 2012).

The issue of equitable benefit among parties involved was also raised by Arnstein (1969), in her ladder of citizenship participation. She uses a popular French wall poster from the 1960s to demonstrate this point (Figure 2) The poster translates as “I participate, you participate, he participates, we participate, you participate, they profit!” This poster rather cynically claims that everyone may participate in researching and making policy, but this no guarantee of equitable benefits for all.

Figure 2. French student poster from Arnstein (1969).

Unexplored, Unresolved Challenges and Degrees of Participation in CBPR

Levels of community participation in CBPR. A relatively unresolved challenge to CBPR is the extent to which true community participation actually takes place in CBPR collaboration. It is important to look at the degrees of participation with help of a guiding framework. There are degrees of participation which Arnstein (1969) described as eight steps on a ladder of citizen engagement (see Figure 3). The most authentic participation was called citizen power, followed by tokenism, which refers to situations in which the community is informed or consulted but has limited control. Nonparticipation is characterized by situations in which the community is said to benefit but in fact is manipulated and has no control at all over the research or partnership.

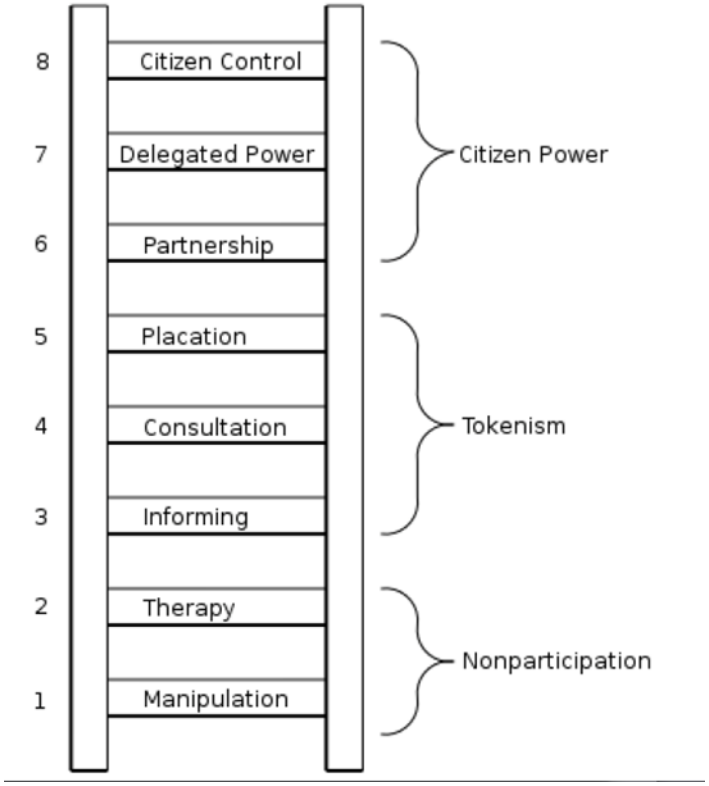

Figure 3. Ladder of citizen engagement (Arnstein, 1969).

Arnstein's (1969) framework is one of the earliest in participatory social science research and intervention and has rarely been explored in public health research to assess the use of participatory research:

A. Citizen power refers to situations in which community members control or are real partners in the decision-making that constitutes the research process. This is considered the most authentic participation.

B. Tokenism is a lesser degree of citizen participation compared to citizen power. At this level of participation, the citizen is not fully engaged in the partnership and research although they are claimed to be; however, they are given a little token at the end of the research. The token could be in the form of an award recognition to appease the member or given minimum compensation. Sometimes the community partner may be invited to be a board member on the research team with little or no power in the midst of all the research.

C. Nonparticipation refers to situations in which the community is informed or consulted but has limited control. Nonparticipation is characterized by situations in which the community is said to benefit but in fact is manipulated and has no control at all.

Degrees of participation are rarely discussed in CBPR literature, perhaps because most CBPR-intended projects are not informed about these levels of participation. Arnstein's (1969) eight degrees as steps on a "ladder of citizen engagement" are illustrated in figure 3 above.

CBPR partnership evaluation as a requirement. There has been very little emphasis on evaluation of CBPR partnership as a requirement by research funding

agencies, and also looking at the guiding principles of CBPR by (Israel et al., 1998). The idea of CBPR evaluation is relatively recent per (Arroyo-Johnson et al., 2015). However, some CBPR evaluations have been performed and yielded beneficial outcomes and conclusions. Arroyo-Johnson and colleagues conducted A case study CBPR and Community Engaged (CE) evaluation about the development and application of CBPR principles for the Missouri CNP, Program for the Elimination of Cancer Disparities, and Minnesota CNP, Padres Informados/Jovenes Preparados I which they administered surveys to compare project versus program operationalization of the principles. The authors found that some aspects of CBPR principles were identified. They concluded that distinctions exist in "operational definitions of CBPR or Community Engaged Research principles at the program and project levels of evaluation…" recommending development of standard CBPR evaluation across partnerships and at the program or project levels. (Arroyo-Johnson et al., 2015 p.9)

In the follow up study on their 2011 realist review on CBPR partnerships Jagosh and colleagues (2015 p.4) conducted another study on retained community and academic participants in their previous study to evaluate CBPR partnership they found that the ripple effect concept in marriage with context-mechanism-outcome configuration (CMOcs) demonstrated that a sense of trust amongst CBPR partners was crucial for sustaining CBPR partnership. They also recommended a continuous CBPR evaluation during partnership to ensure sustainable partnership outcome and benefits.

A case study of the Detroit Community-Academic Urban Research Center (DCAURC) between 1992 and 2007 also emphasized the importance of evaluation of

CBPR projects. The DCAURC was a 10-member organizational partnership, including the University of Michigan School of Public Health, and nine community organizations that was funded by the W. K. Kellogg Foundation to undertake a collaborative, community-based participatory research and intervention project to benefit the health of Detroit families and communities. Israel and colleagues (2001a) used annual in-depth interviews and close-ended survey questionnaires throughout the project and generated ample data to measure progress and outcomes, including dimensions of benefits and cost of participation, impact of partnership and sustainability (Israel et al., 2001a). The authors presented this evaluation as a success story in CBPR partnership, progress and sustainability evaluation, and they argued that evaluating the degree of community partnership engagement and equitability is always important in view of the power differences among participants (Israel et al., 2001a).

Unclear ethical protection of community as partners. Another largely unexplored challenge to evaluators of CBPR relates to the ethical protection of community participants. Institutional Review Boards (IRBs) tend to use the Belmont guidelines for ethics in biomedical research (HHS, 2013; NCPHBBR, 1979), which were designed to protect human subjects but not communities (Flicker et al., 2007). More effective community protections in CBPR projects have been proposed (Schulz et al., 1997) but not widely implemented, especially in minority communities (Jagosh et al., 2011; Stacciarini et al., 2011). Initiatives have been put in place to ensure the protection of indigenous, vulnerable research participants (Grignon et al., 2008; Navajo Nation IRB, 2003; NCPHBBR, 1979), and research funding agencies such as the Centers for Disease

Control and Prevention (CDC) and the National Institutes for Health (NIH) have sponsored ethical committees to ensure protection of the community in the process of research collaboration with academic researchers (Grignon et al., 2008). Jagosh et al's study demonstrated that there is still a widespread lack of authentic ethical protection for communities engaged in CBPR research practice.

The relevance of institutional and ethical committees examined by Juritzen et al (2011) observed that claims of these ethical institutions to protect research participants in CBPR. The authors found some loopholes as there continue to be an existence of bureaucratization in these institutions which hindered authenticity and purpose of research. Such problems of power could hurt research, researchers, the vulnerable participants, and the marginalized community as there may be risk of coerced participation in and administration of the research resulting in unrealistic research findings. Shore and colleagues (2015) also made recommendations for IRBs to be amended to suit CBPR partnerships and projects.

CBPR program/partnership sustainability and other challenges. Another major challenge in CBPR that still keeps CBPR and Community Engaged researchers and community partners pulling their hair is sustaining programs after funding ends, as well as ensuring community commitment throughout the research process. Some researchers have succeeded to a certain level at ensuring sustainability, however it takes extensive capacity building, commitment, sacrifice and engagement and involvement of community members in all phases of the research partnership particularly in the prioritization and research design of the issue to be researched and resolved. (Jagosh et al., 2015). Other

challenges found include diverse institutional goals, poor communication, different perspectives in formal processes such as grant applications and reports, and the slow time span for real time intervention results (Anderson et al., 2012; Magwood et al., 2012).

Summary

This chapter has highlighted the strengths of authentic CBPR partnership and some challenges with these partnerships. It was noted that CBPR in its purest form may promote health and prevent diseases and health complications through programs that are culturally tailored to the target population and partnering communities, especially low-income and minority communities. Failure to appropriately implement this approach to research or any form of research may hinder progress in health outcomes, and when unethically conducted, may raise trust issues within the community. Trust issues in these communities would hinder further research and possible intervention ventures, thus putting the lives of individuals and the community at higher risk for diseases and mortality. The literature also showed a gap in evaluating CBPR partnerships and assessment of levels of participation in CBPR projects within communities, using a unique and universal framework and standard. It also presented some continued multi shades of CBPR as well as challenges in undertaking authentic CBPR partnership and collaboration among academic researchers and community partners. This study sought to find answers to some of the questions relating to these gaps, using the community coalition action theory, Arnstein's (1969) ladder of participation, and the CBPR guiding principles as guides.

Chapter 3: Research Method

Walden University's IRB approval number for this study was 11-14-14-0198380. I examined the perceptions of academic researchers and community participants in CBPR projects in African American and Hispanic low-income neighborhoods of a major metropolitan area. Informed by the CACT, I explored the partnerships, process, and challenges faced before, during, and after community partnerships, the levels of involvement, and the extent to which CBPR guiding principles were utilized authentically from the partners' perspectives. I also looked at the extent to which the research institutions, through their ethics committees or IRBs, are able to ensure that not only the lives and interests of research participants were protected but also those of the community participants and their individual leaders.

The potential benefits of CBPR have been described in the literature, but little has been done to examine and assess the levels of participation during CBPR partnerships between academic researchers and community partners. This study was guided by a conceptual framework that included the CACT, the guiding principles of CBPR (Israel et al., 2003), and the degrees of participation (Arnstein, 1969). In this chapter, I describe the qualitative method and phenomenological design that guided this study.

Nature of the Study

I used a phenomenological design to explore the first-person lived experiences (Husserl, 1989). In this study, the phenomenon being examined was participation in CBPR partnerships by university researchers and community leaders in a major U.S. city. Data were collected using in-depth in-person or phone interviews.

Research Design

Phenomenology deals with experiences and meanings "to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" (Giorgi & Giorgi, 2003, p. 27). The phenomenon is explored through rich descriptions or narratives that can illuminate the lived world. The aim is to see things according to participants' perspectives. In this case, the phenomenon being examined was community-academic partnerships in CBPR in a major U.S. city. The phenomenon explored was the lived experiences of several individuals, using mostly data collected from individual interviews (Creswell, 2007). The phenomenological approach is rooted in philosophy, psychology, and education, and significant statements and experience from identified individuals are analyzed in a phenomenological study.

This study was guided by the community coalition action theory (CCAT) (Butterfoss & Kegler, 2002) to explore the challenges experienced before, during, and after the process of CBPR and specifically the issue of trust building and sustaining the partnership and the program after the study. Other expectations in CBPR partnership were explored using Israel's (1998) principles of CBPR, and the level of involvement in these CBPR partnerships was examined using Arnstein's (1969) ladder of citizen participation. Data were collected using in-person in-depth interviews with seven academic researchers and six community members who had at least one year of experience in CBPR partnerships.

Measures and Recruitment

All community participants in the study were from minority communities characterized by poverty. One of the reasons for this focus was that most research and interventions take place in underserved communities characterized by scarce resources, poor health, and little or no access to proper health care.

Recruitment of participants was done through emails sent to a community-campus partnership groups in the U.S. city. Participants were also recruited through referrals and in-person at community/academic networking events that CBPR participants from academia and community partners and members attended. I successfully recruited 13 participants, seven academic researchers and six community members, to provide their views on the interview questions pertaining to levels of participation using CBPR's nine principles, levels of involvement in their CBPR partnerships, and other questions addressing various aspects of community-academic partnership in their CBPR experience. Titles of projects and institutional affiliations have not been disclosed to protect participants and avoid any personal and professional conflicts.

This study was informed by community action coalition theory (CACT) (Butterfoss & Kegler, 2002), which is used to establish partnership agreement of diverse individuals and organizations in collaboration to address community problems. The CACT provides a framework for examining the processes of partnership building, shared governance, and the outcomes of CBPR projects. A focal point of the theory is promotion of long-term commitment among partners after a project is completed, to ensure continuity, synergized coalition formation and functioning, and establishment of

community and organizational change (Butterfoss & Kegler, 2002). The CACT model and principles also provide an underlying framework for clarity on the structure, process, and results experienced by effective and authentic community coalitions in addressing intermediate and long-term health outcomes.

Community partners and academic researchers were asked to answer questions relating to the application of the noted principles in conducting CBPR collaborative research and also report on various levels of involvement and challenges experienced during and after the research process and partnerships. Arnstein's (1969) degree of participation classification was used to measure the levels of involvement in the CBPR projects.

Role of the Researcher

I planned, designed, and carried out the study, including collecting the data through in-person and phone interviews, transcription of the interview recordings, and analysis of data. I ensured that all ethical standards were maintained throughout the research process.

There was a possibility of personal bias as a result of my employment experiences and interactions with community members who have experienced CBPR or have been invited to participate on CBPR projects by academic researchers, and who may hold strong views about CBPR and research in general with neighboring universities. In this position, I witnessed one CBPR partnership that that did not follow the CBPR guiding principles with its community partners. I also witnessed challenges faced by community

partners and the politics involved in this collaboration. The result of this behavior has led to distrust by some community partners.

I saw an opportunity to study a problem that was expressed by both the community members and academicians in this form of research partnership, a problem that mostly related to relationship and trust building as well as sustainable partnership and projects. I also saw the need to look at different levels of involvement from both partners in the CBPR partnerships, the benefits from the partnerships, and the association between involvement and benefits. To address these issues, I remained unbiased throughout the process of participant recruitment, data collection, and data analysis by recruiting different participants, avoiding coercion during data collection, analyzing data transcribed verbatim, and performing member checks for data accuracy.

Methodology

I conducted a qualitative phenomenological study examining lived experiences of community members and academic researchers in CBPR partnerships. The study was guided by the community coalition action theory (Butterfoss & Kegler, 2002), Israel's (1998) guiding principles of CBPR, and Arnstein's (1969) degrees of participation.

I used a purposive sampling strategy. Creswell (2009) posited that purposive sampling strategy in qualitative research assists the researcher in selecting the best participants for the study to answer the research questions. This form of sampling allows the researcher to recruit from a specific group of individuals based on study objectives (Rudestam & Newton, 2007).

Participants

I explored the perspectives of community members and academic researchers who were currently involved in or who had been exposed to the CBPR approach to research for more than a year and who spoke and understood English. Participants were recruited through a community-campus research email group in a Midwest U.S. city, community and campus networking events, and referrals. Interested participants were screened through initial phone conversations.

Participation was restricted to those involved in CBPR for more than 1 year, with community partnerships involving low-income communities and academic institutions in a Midwest US city. Recruitment was not limited to low-income communities to get a broad perspective on CBPR partnerships. However, community participants came from mostly minority and low-income communities while academic researchers were from four major universities in Chicago. The 1-year experience in CBPR requirement was to make sure that adequate time had been spent in building partnership and project/program planning and to ensure that some sort of implementation had taken effect. Participants had to speak and understand English to facilitate communication during the interviews.

Seven academic researchers and six community members were invited to participate in the study. The number of participants increased because I was looking for more data from both sides of the partnership. I realized that academicians were also eager to have their voices heard regarding the challenges of carrying out this type of research. Participants were also recruited through referrals or in person at community/academic networking events that CBPR participants attended.

Interview Questions

In-depth interviews were conducted on topics that included perceptions of process and outcome, challenges, and the degree of participation at various stages of the CBPR partnerships. Prior to the study, after IRB approval, I developed the protocol and tested the interview instrument through a community partner and a faculty member at a university in Chicago. I found that the original set of questions would be too lengthy with many sub-questions for each main question. As a result, I reduced the number of sub-questions and designed more open-ended questions resulting in 12 total. The questions were also revised based on the length of time, quality and quantity of the pilot data from the interview questions from the pilot interview sessions.

The interview questions were adapted from Green's (2004) original CBPR assessment tool, which was modified to suit the purpose of this study. I obtained written permission (Appendix C) from Dr. Green to use and modify the assessment tool, which was approved by my dissertation committee members.

Modification of the interview questions focused on levels of participation drawn from Arnstein's (1969) ladder of citizenship participation, CBPR principles (Israel et al., 2003), and the community action coalition theory (Butterfoss & Kegler, 2002). Interview questions stemmed from this study's research questions and gaps in the literature including unexplored challenges, ethical issues, success factors, and recommendations for CBPR best practices.

This study included three research questions:

Research Question 1: What are the perceptions of academic researchers and low-income community members about their experience of the process of CBPR before, during, and after their partnerships?

Research Question 2: What levels of participation were experienced by participants at each stage in the research process?

Research Question 3: What challenges, ethical issues, benefits, and outcomes have participants experienced in their CBPR partnerships?

Ethical Protection of Participants and Confidentiality

Data obtained from interviews were securely saved and protected on my private home personal computer. All completed consent forms were also securely stored in a private locker at my home. Interviewees' personal and other identifying information were de-identified on the transcripts, and the recordings are kept securely locked and confidential. All participants signed two informed consent forms prior to interviews, one for me and one for each participant, which indicated the study expectations. Signed consent forms were emailed to me by those who preferred phone interviews, whereas those who preferred face-to-face interviews provided their signed consent forms in person prior to their interviews. Participants were assigned a letter A through Z with a general identifier (Resident or Professor) for community participants and academic participants, respectively. The names of participants' affiliations were also de-identified on the data and final analysis to ensure confidentiality and avoid personal and professional conflicts. The consent form indicated that participants could participate or

decline participation at any stage of the study. All data obtained during the study are stored in a locked drawer in my home and will be destroyed 5 years after the study.

As for the digital audio recordings, combined consent was obtained to record interviews and take notes after which transcripts of their statements were sent to respective participants for review and final confirmation before any further progress. These data will be destroyed two years after the study using appropriate methods. Questions relating to geographic location and address of participants and their affiliations are not included in the study.

Research Procedures

Data was collected using the following sequence of events as shown in Figure 4.

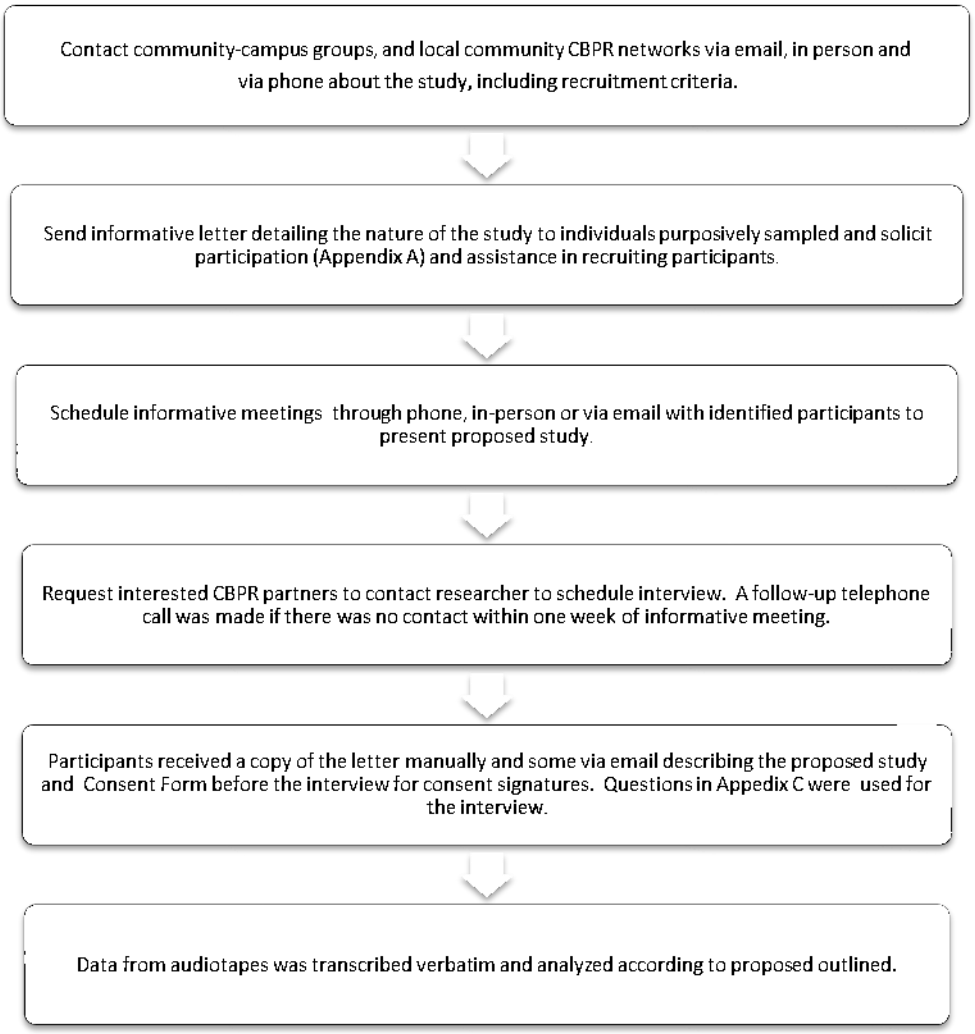

Figure 4. Study sequence.

Data Collection

An In-Depth Interview Protocol (Appendix A) and a specially developed questionnaire (Appendix B) were developed to guide the interviews. Notes were taken by interviewer (researcher) during each interview session, and sessions were also audio recorded. Interviews were completed within three months: from December 2014 to

February 2015. Sessions lasted between 39 minutes to 74 minutes. The lengthiest interview sessions were mostly by academic participants as they tended to have more details on the topic and as such used more time to answer all questions in detail.

Data collection followed the exact protocol presented in the dissertation proposal chapter 3. This researcher scheduled interviews for participants according to their date, and location convenience, and a reminder phone call was made to participants by the researcher 24 hours before the scheduled interviews. All participants confirmed their scheduled date and time. All participants were asked the same set of interview questions.

Some challenges in data collection with face-to-face interviews for some participants were schedule conflicts with work and other responsibilities and also interview locations. As a result, after discussion and approval with the dissertation committee, the researcher requested a phone interview in addition to the mode of data collection from the Walden Institutional Review Board, which was approved. This made the rest of the interviews seemingly easy by phone, which were recorded using a conversation recording phone application on the researcher's Android phone. Prior to the interviews the researcher tested a phone conversation for clarity to make sure data obtained during the interviews were clean.

Each recording was immediately downloaded using a USB and saved on the researcher's private locked computer. To obtain rich data, the researcher interviewed 13 participants instead of 10 as originally planned, six participants from the community and seven from academia. Each participant received a $25 gift card for participation.

Data Analysis

Audio taped interview data were immediately downloaded using a USB onto the researcher's private locked computer, replayed verbatim and transcribed verbatim shortly afterward by the researcher. Texts of the transcripts from the interview data were analyzed by the researcher using NVivo 10 for qualitative data analysis for accurate coding and identifying themes, linking participants' responses to the interview questions. The researcher used a hybrid of priori codes (pre-set codes). Priori codes come from characteristics of the phenomena being studied. Ryan and Bernard (2003) recalled that priori codes are coding methods that Aristotle described as a first cut at understanding any phenomenon. The emergent themes are ideas, concepts, actions, relationships, meanings, etc. that come up in the data and are different than the priori themes (Bulmer, 1979; Maxwell, 1996; Strauss, 1987). These codes derived from existing theoretical frameworks served as a guide to better understand the current CBPR phenomenon (Israel et al., 2003; Schulz et al., 1997) through CBPR principles, Arnstein's (1969) ladder of citizenship participation, community action coalition theory (Butterfoss & Kegler, 2002), the literature review, and the research questions to confirm the CBPR phenomenon being studied. The themes were then categorized into main and sub categories.

Codes, therefore, were categorized based on similarities and frequencies from various interview responses and were examined across challenges, barriers, strengths, weaknesses, overall success factors, satisfaction and dissatisfaction, levels of participation, equitable partnerships, sustainability of projects and partnerships after funding ends, perceptions of CBPR, building and maintaining trust, community buy-ins,

forms of compensation, ethical issues, sense of empowerment, colearning experience, collaborative efforts, partnership initiations and recommendations. Due to the large number of codes with similarities, themes were therefore contextually categorized under main and sub themes as seen in chapter 4.

Participants received hard copies of their various transcripts for member-checking to ensure data accuracy. Hard copies were provided to guarantee that participants received them and could easily make any corrections on the scripts. Also, it was less stress for participants to make copies for themselves. Lincoln and Guba (1985) and Creswell and Miller (2000) found that member check is a crucial technique for establishing credibility in qualitative research. However, this technique is controversial as it has its cons. Ronald Hallett (2012 p. 31) in his book "Dangers of Member Checking" highlights 3 main cons of member checking presented by Locke and Velamuri (2009): (1) little guidance exists concerning how to conduct member checks; (2) lack of awareness about the implications of study design choices or how to deal with participant feedback; and (3) limited understanding of the relational complexities and epistemological ambiguities. (Hallett, 2012 p. 31). It could also lead to participants changing their minds from their previous responses to the research interview depending on their mood for that day; it is lengthy process and can be difficult to get feedback and commitment from participants.

Readers of the study should be aware about the researcher's position in the study topic, per Creswell's recommendation (2009). The researcher in this study has witnessed some community-academic collaboration classified as CBPR. Being in academia and

acting in the capacity of a department's community health program coordinator, the researcher experienced different campus-community partnerships in relation to her job responsibilities and other public health programs and projects. The researcher upholds authentic CBPR partnership as a sure means to resolve health inequity not only in minority communities but in communities in general. However, the researcher of this study understands some of the challenges faced in maintaining CBPR partnership authenticity. This researcher, however, kept possible biases aside from this study to stay true to the goal of the study.

Summary

This chapter described the design for this qualitative study using a phenomenological approach. The phenomenon being examined was participation in CBPR partnerships by university faculty and minority community leaders in a major American city. Data were collected using in-depth, in-person, and phone interviews providing an opportunity to get lived experience of partners in CBPR approach to research. The participants selected for this study were community and academic partners of CBPR projects, programs, or study, who had been in partnership for at least a year in Chicago and who understood and spoke English.

The study methodology used to collect data also provided opportunity for in-depth data through probing and follow-up questions not clearly answered by interviewees. The data were analyzed by identifying individual and group descriptions of the experience to understand the overall meaning of their experience. Verification consisted of clarifying researcher bias and member checking.

Chapter 4: Results

Although many researchers have reported the apparent success of CBPR in promoting health and preventing disease, little has been done to evaluate specific projects looking at the levels of involvement by all partners and the authenticity of the CBPR partnership. CBPR and research in general raise hopes among community organizations, with promises of protection and health improvement for the involved community. If these hopes and promises are not met, trust is broken and future opportunities for other researchers may be compromised.

The purpose of this study was to examine the application of CBPR in one city from the perspectives of participating academic researchers and community members/partners, specifically their levels of involvement in and the authenticity of the CBPR partnerships as well as other challenges and recommendations for CBPR best practices. Special attention was paid to the role of academic ethics committees (IRBs) in ensuring that research participants are informed of the risks involved in participating in the research and are protected in all aspects of the research. Interview questions were adapted from Green's (2004) CBPR assessment tools and modified to fit the purpose of this study.

Thirteen in-depth interviews were conducted with seven academic researchers and six community members/partners who were experienced in CBPR. Using the phenomenological approach to data collection, I interviewed participants about their lived experiences relating to their CBPR partnerships, levels of involvement in the process, challenges, concerns, successes, and recommendations for successful partnership

practices. Interviews lasted from 39 to 72 minutes. Data were analyzed using a hybrid of a priori and emergent themes associated with the principles of CBPR laid down by Schulz et al. (1997), Arnstein's (1969) levels of citizenship participation, and the community coalition action theory (Butterfoss & Kegler, 2002).

Recruitment

Participants were recruited through emails sent to researchers and community leaders whom the researcher had met at community/academic researcher networking events or heard when they presented their CBPR projects in the community. Academic participants came from four major universities in a Midwest US city and community participants came from minority and mostly low-income communities. Participants were also recruited through referrals. A total of 13 participants who understood and spoke English were recruited: seven academic researchers and six community members/partners. To preserve confidentiality, the titles of their projects and institutions were not disclosed.

All participants were asked to answer questions relating to the application of the principles in conducting CBPR and also discuss various levels of involvement and challenges experienced during and after the research process and partnerships. Arnstein's (1969) degree of participation classification was used to measure the levels of involvement in the CBPR projects. An in-depth interview protocol (Appendix A) and a questionnaire (Appendix B were developed to guide the interviews. All participants were asked the same set of questions. Table 1 presents the participants' profiles.

Table 1
Profile of the Participant

Community Participants: Residents	Academic Participants: Professors
A. Center director of a community agency	A. Faculty and program cofounder
B. Former director of operations at a community-based agency	B. Faculty and program director
C. Program director at a church-based community agency	C Academic project director
D. Community staff on a CBPR project	D. Faculty and project coordinator
E. Cofounder of a community based program	E. Faculty, physician.
F. Program director	F. Faculty and project coordinator
	G. Faculty

Data Collection and Storage

I conducted and recorded the interviews and also took notes. Sessions lasted between 39 and 72 minutes. Academic participants tended to have longer interview sessions because they had more details to share on the subject matter and required more time to answer all questions in detail.

Challenges occurred in arranging face-to-face interviews with some participants due to their schedule conflicts with work and other responsibilities. After discussion with

and approval from my dissertation committee, I requested Walden University IRB permission to conduct phone interviews as an additional mode for data collection; this request was approved.

At the interviews, I greeted participants, thanked them for agreeing to participate in the study, and introduced myself as the sole researcher. For in-person interviews, I began the process by giving each participant two copies of the consent form for his or her signature; one was retained by me, and the other was returned to the participant. For phone interviewees, I emailed the consent form prior to their interview. I asked each participant if he or she had any questions about the consent form or study and if he or she was still willing to participate. I following the interview protocol (Appendix B) during the interviews. I interviewed each participant using 12 semi-structured questions adapted from Green's (2004) CBPR assessment tool and modified to answer the research questions. At the end of each interview, I allowed participants to share additional information they wanted me to know about their CBPR experience.

The phone interviews were recorded with a recording application on my Android phone. Each recording was immediately downloaded to my private locked computer. I played and reviewed each audio recording after each interview to ensure that the recording was clear and to familiarize myself with the content and logic of the responses. The recordings were later transcribed verbatim. I provided each participant with a $25 gift card and promised to provide a written abstract at the end of the study; I also agreed to a possible presentation at a local event, and I am yet to make such arrangement as I await appropriate opportunity.

Post Data Collection Observation

Lincoln and Guba (1985) and Creswell and Miller (2000) indicated that member checking is crucial for establishing credibility in qualitative research. However, this technique is controversial and has its pros and cons (Locke & Velamuri, 2009). Member checking could also lead to participants changing their responses depending on their mood on that day. Another problem was the lengthy process and the difficulty in getting feedback after interview commitment from participants. I found that providing participants with hard copies of transcripts reduced their burden of having to print copies themselves, which facilitated feedback.

Data Analysis

Following each interview, I immediately downloaded the audio-taped data using a USB cord connected from the phone to my private locked computer, and shortly afterward transcribed the interviews verbatim. Texts of the transcripts were transferred into the NVivo 10 software for qualitative data analysis and coding, which involved identifying and color-coding themes and linking participants' responses to the interview questions.

Codes were chosen based on similarities and frequencies from various interview responses; topics included challenges, barriers, strengths, weaknesses, overall success factors, satisfaction and dissatisfaction, levels of participation, equitable partnership, sustainability of projects and partnerships after funding ends, perceptions of CBPR, building and maintaining trust, community buy-ins, forms of compensation, ethical issues, sense of empowerment, colearning experience, collaborative efforts, partnership

initiations, and recommendations. Due to the large number of codes, those with similar themes were categorized under main and subthemes.

Participants received hard copies of their interview transcripts to ensure data accuracy. Hard copies were provided to guarantee that participants received them and could easily make handwritten corrections on paper.

The data analysis revealed 46 themes. The lists of these themes by research question are summarized below, and subsequent sections present the findings, organized by research question and themes.

Analysis of Themes: Research Question 1

The first research question was as follows: What are the perceptions of academic researchers and low-income community members about their experience of the process of CBPR before, during and after their partnership? Twenty nine themes emerged to answer this research question.

Perceptions and Knowledge of CBPR

Theme 1: CBPR is research where academics get access to community experience. Some community members and academic researchers referred to CBPR as "grass roots" research performed from the bottom up with an emphasis on community member participation and engagement. This research gives researchers community access, allowing them to understand community realities and to find solutions for identified community problems. Like most participants, Resident B called CBPR a collaborative effort between academia and the community:

> CBPR specifically allows institutions, educational institutions, higher learning institutions, to participate at a grass root level with residents in particular communities to make change in areas that are identified and assisting folks in further human development. Moreover, it allows access for academia to really get a qualitative feel for their research and give them a baseline and a real look at what is truly going on in comparison to book theory.

Theme 2: CBPR is collaborative, with good community engagement. Another theme drawn from participants' perceptions of the CBPR was that CPBR partnership involves all partners equitably in the process to find solutions to community needs. Professor A reported that CBPR is a collaborative type of research between researchers who are affiliated with or are active members of the community, and all partners take ownership of the research and project from start to finish:

> My understanding of CBPR is truly creating a partnership between researchers who are usually active additions and members of the community they can be related members of the community, or they can be members of the community that are affiliated with an organization. To create a partnership, so a partnership that's an equitable partnership, in that everyone has an equal voice and everyone's voice is heard equally. To improve, for example, in public health, to improve health outcomes or whatever of the community on whatever topic…to take ownership, equal

> ownership of this topic and maybe involved in some type of project equally to address that issue that the project is focused on.

The word "collaborative" was commonly used by participants in different contexts. Unlike the above definition from Professor A, Professor B and other professors and some community participants stated that CBPR is collaborative research between community members and academic researchers where there is greater chance for social change in the community. Professor B defined CBPR as follows:

> To me, the CBPR is about making sure that the people who are impacted by research have a voice and a role, in designing, in conducting, and using that research. so it's honoring the knowledge….It takes both academic expertise and community expertise to produce the research that has the highest chance of being relevant and usable to make change in community.

Resident C supported the above statement and highlighted that CBPR is collaborative between academic researchers and community partners/members with the opinions of the community being taken into consideration. Resident C also raised an important point, which is that research is not necessarily initiated or led by academic researchers, as seen in the following definition:

> I like to view CBPR as it has parity between academia and the community. It is a research practice that utilizes the viewpoint of the community and the researcher…so it is sort of a collaborative

> relationship. That's the word that I like to say. It's collaborative, and it is not necessarily driven by academia not necessarily driven by the community. It is people coming together, meaning researchers and the community who come together to decide on a research topic and then design the methodology and research design together.

Theme 3: Research has to benefit all partners. Several participants stated that a CBPR partnership should provide solutions to problems identified in the community, solutions that could extend to policy adjustment or impactful change in the community. Professor C stated the following:

> So, they (community) then are the people who should experience the benefits of that research. It can also be research to identify causes or potential solutions for problems that will require policy, public policy intervention, or it could be private company corporate intervention, but ultimately it should benefit its research that's done to benefit the community, done with input, meaningful input from community organizations to solve their own problems.

Theme 4: Community trust in university researchers has to be earned. A major theme was lack of community trust in the university researchers. Some community participants indicated that the community was not trusting of academic researchers as a result of poor relationship-building. Academic participants had mostly positive perceptions of their CBPR experience, though they also expressed some challenges as highlighted later in this chapter. Resident B said:

> We serve as the buffer between the community and the institutions….People in these communities do not trust the university, they don't trust, I mean they just don't.

Participants also expressed opinions regarding "lack of sustainability" in the programs or partnership when funding ended, "poor communication," "poor relationship building," "racism," "lack of concern" from the universities about the communities, and the shortage in partnership profits and benefits for the community.

Resident B, like Resident C, indicated that some universities, particularly one major research university in Chicago, lacked authentic concern for low-income minority communities and cared mostly about researching them. He also expressed that these communities have been over-researched by universities with few problem-solving successes. He said since these universities had money to offer, they targeted desperate populations through community organization for tokenistic types of research, and he compared community participants to "guinea pigs":

> You know we make a joke a lot. We joke a lot about how much universities come to study and do research on specific communities and more specifically the African American and other communities of color. We make a joke about it. And the University of ____ has, they have a lot of money, and so the first thing that they do is say, 'Ok, we're going to pay you x amount of dollars.' And folks say, 'Ok,' and they are on board, but they tapped into the only population, they tap into the populations that really don't have

anything going for themselves. And so it's the last thing, they need a couple of dollars and so. I akin it to guinea pigs.

Resident A also felt the pressure from his community about lack of trust in university researchers; he indicated that he felt the need to be particularly "sensitive" about the research aspect of his partnership at all phases of the collaboration since his community already had a "bad perception" of this particular research university "…of being researched and not participating" fully in the process: "… I was very sensitive to that and wanted to make sure I had some ownership in developing the research from all ends. So, I participated in all aspects."

Theme 5: Participatory programs and partnerships tend to lack sustainability. The issue of sustaining programs and partnerships upon the end of funding was presented by several participants as a public health problem faced both by community members and academic researchers. This also tied in to the issue of CBPR partnership and project sustainability, as most academic researchers do not see the need to maintain a relationship and partnership when there is no funding or/and project prospect. However, community members see partnership and project sustainability as crucial in building and maintaining trust between academia and the community. Resident B expressed his frustration about the lack of sustainability and lack of commitment to partnership after study and funding ends, "…once you have completed a program or study, what's next?-And, you know, that's the million-dollar question."

Professor B expressed the opinion that often researchers focus too much on the

scientific research aspects of the project and not enough on the partnership process and relationship-building of CBPR, which may be important down the road in preventing conflicts and misunderstanding. She also raised the need for a Memorandum of Agreement from the start of partnership to define roles and responsibilities in the partnership.

> I think paying attention to process, a lot of times people just want to get to the research project - the hard stuff that the rigor of science - but if you take the time at beginning to pay attention to the process, potentially set up agreements like memorandum of understanding (MOU), or roles and responsibilities, a lot of times those can prevent conflicts from happening down the road or misunderstandings in the communication down the road.

Theme 6: Research dynamics and IRB requirements can be challenging. Professor F expressed his perception of CBPR as a research process that is too complicated to adhere to. He indicated that the community and academic researchers work at different paces. While the academic has to follow strict IRB and research rules, which sometimes delays the process, the community often wants immediate solutions to their problems:

> The two different worlds, if we can call it that, operate at a much different pace. The community often wants something done, and they want it done immediately. They have an immediate need, an expressed, felt need, and they want to handle it. With academia, you

> say, oftentimes, 'Oh, this is this great idea. This would be this great partnership. Can you wait three months while I get IRB clearance?' and then they say, 'Sure.' And then you get it, and you go there, and you say, 'Okay, here's what they (the IRB) said (about recruiting people),' and then they (the community) say, 'Yeah, but we like to recruit people this way.' And then you say, 'Okay. Well, can you wait another month and a half while I get the IRB amendment?'…. not to totally bash the IRB, but things move at a different pace… they make it seem like -- okay, I guess what I'm saying is that partnerships take time to build, right? And this is where I was going with that timing thing. The expressed and felt needs of the community sometimes can't wait for academia to catch up.

Another key CBPR perception raised by Professor F was the IRB requirements for confidentiality in relation to study participants. He indicated that the IRB does not allow community participants to get credit for their participation in the research because of their requirements for confidentiality, and yet if the names of participants are not disclosed, this does not help produce change in their community because they are invisible:

> Why can't people be recognized for their contribution?...Surely you shouldn't try to hide that….How paternalistic is it for me to say, 'I know what's best for you, by the way, open up your life to me so that I can write about it without giving you credit for it?' That's my

> biggest issue with the structure of the IRB. You're protecting people, oftentimes, from themselves, which diminishes their contribution and role and benefit in the program.

Professor I shared the following issue with adherence to research methodology and design. The community, according to her, does not understand the dynamics of the science of research and the concept that projects must stick with original research design and proposal. Thus, they may wish to conduct research activities in a different way by adjusting the research plan -- with recruitment, for instance. She said:

> They (community members) don't understand the dynamics of the science and, also, sometimes will want to change our design, so that it fits with what they think needs to be done in order to recruit….Changing the design changes the focus of the study, so we have to make sure that they understand (the need for) uniformity among all four partnering groups. One group may decide, I think its best that we (change something, but) if we change one group, we have to change other groups, and in fact we can't change one because of the research design, which is already set up. That's the largest barrier.

Professor E expressed that sometimes efficacy studies do not necessarily work out realistically, and community members must therefore be involved in the planning of the intervention or research in order to maximize the possibility for success:

> Those efficacy studies often times will not work in those real-world conditions so you have to… be involved in the planning of what takes place in order to figure out whether or not the changes that are being recommended are changes that one can buy into.

Professor E also expressed concern about the ethical issues related to CBPR and the Belmont report requirements for research and suggested an adjustment to IRB requirements for CBPR:

> The Belmont Report was in the 1970s; it was developed primarily for human subjects' protection in research studies that have to do with mostly with testing of devices and medication et cetera and grew out of some of the ethical challenges that were in place with the US Public Health Service….Obviously, the field of research has evolved and the question is whether or not in 40 years hence is it time to reexamine what is there and perhaps make some additions.

Theme 7: Community members may lack power and academics may intimidate them. Resident C cautioned against the use of the term "empowerment" in this context. He said "empowerment" was a strong word that required long-term commitment, sustainability, resources, and community involvement in all aspects of the research and benefits. He said it takes time to measure outcomes. To him, disseminating information to the community does not guarantee community empowerment when it is brief and involves little or no effort to build relationships and engage the community involved:

> I'm very cautious of the word when we say empower because if you're going to empower someone that takes a while and it is more than information, it has to do with resources and as we know with research, again, only so many resources can go into the community, so I don't like to use the word empower. I would say enhance and provide information. Because if you were to empower the community that means that the community would be doing all the research…I can't say they were empowered. I think empowering takes a lot of engagement… power includes research design, power includes money, power includes knowledge, power includes being a principle investigator, and very few research projects are technically doing that.

Resident C also indicated that community partners tend to be intimidated by academic researchers; this prevents them from bargaining appropriately in the partnerships and, as a result, they are left with minimal compensation:

> Sometimes community members are intimidated by academia, and they don't request adequate funding. However, my philosophy is whenever I meet with a researcher, I already know. I may not know an exact amount, but I know how much, this is my community now, I will not partner with an academic entity unless there is some sort of compensation.

Resident B also did not feel that he or his community was empowered by their partnership with academia. He said that once the research was completed, the academic

researchers left them with no explanation, results, or next steps. He raised an issue of continuity and sustainability in partnership and programs:

> Honestly, I cannot say that. I cannot say that…once it's done it's done everyone packs up their blankets and goes home. The community is left in the same predicament that is was, maybe a few may have benefited health wise but comprehensively the community isn't any better than when folks came in there to do the research.

Theme 8: Affected communities face limited resources (especially financial and human capital) as well as poor health. The communities in partnership with academic researchers are mostly characterized by poverty with limited access to resources. In one case, community members strategically initiated a CBPR partnership with academia with the intent to get their voices heard through research and advocacy as well as secure potential linkages to the scarce resources they need for their community to thrive.

Participants described the communities involved in this study as experiencing a lack of resources. These resources could be seen from the point of view of plain poverty as well as lack of, or inadequate, human, financial and social capital. These needs draw the community to seek assistance from academia in different areas such as research collaboration, social entrepreneurship, and other forms of intervention. Resident A, a community activist, highlighted that his community initiated a CBPR collaboration with academia to help improve the social and economic condition of his community

through research and community awareness; this collaboration yielded positive social change for the high school students involved. He said:

> We were aware that there was a major university…south of the _____ that has a lot of wealth and potential…where community members are benefiting off their footprint in the neighborhood. So, we decided, you know, let's bring that west of the _____ where resources are limited, where there would be academia, financial, whatever the case may be. And then that was our goal, that was our plan … to partner with this one university and have them participate with us in some like-minded CBPR projects where we would be able to leverage their expertise and they would be able leverage ours at that point specifically.

Resident B expressed similar sentiments:

> OK. So we are in an economically challenged, fiscally challenged, morally challenged, education challenged population. So, some of the characteristics vary. They are very wide ranged depending on the person's age, in addition to their education level. So, specific characteristics, we are looking at 99.9% who are African American.

Research has also shown that ethnic minority communities are at higher risk for health issues, particularly cardiovascular and other chronic diseases. In the United States, these communities mostly comprise Hispanics and African Americans. It is therefore understandable that the communities represented in this research fall under these categories: characteristics which attract researchers from all walks of life and academia

particularly, with ambitions for ground-breaking research and new solutions to the health disparities and other problems faced by these communities.

Communities involved in this study, therefore, were mostly ethnic minority communities; Hispanics and African American communities in particular are the most affected by chronic diseases and lack of, or limited access to, basic socio-economic and human capital, especially in health care. This explains the potential for research studies and public health interventions in these communities through partnerships. As Professor B pointed out, "Every community is affected by strokes, you know…but this particular project is focused on African American and Latino communities and especially taking in consideration, that these are communities that are lower socio-economic status."

Theme 9: Language barriers and lack of documentation hinder communication and productive partnerships. The issue of language as a hindrance to access to health care for immigrants has been extensively documented in the past. Some study participants highlighted this theme as an experience during their CBPR partnership, especially as it relates to communication with participants in their research and interventions. Unless there is proper and bidirectional communication and understanding between the giver and the receiver, there is bound to be a poor output or reception from the perspective of the communicator. Some academic participants in this study overcame this barrier by strategically collaborating with bilingual, culturally-appropriate partners who could be trained to provide the type of research services required for the projects to be accomplished. As noted by Professor A, "A lot of

them in Hispanic/ Latino community, a lot of those members do not speak English, so we have a larger proportion speak only Spanish and small proportion that speak English." Professor C said:

> The work we have been doing here since I came here in '08 has been equally divided in partnerships between organizations that are predominantly Latino and serve primarily Latino communities and those that serve predominantly African American communities….They live in communities that don't have the resources where they can walk to the corner the supermarket, nor do they have three or four supermarkets in the community where they can get access to relatively affordable healthy food. So, that is the kind of community; they are low-income; they are minority; they don't speak English well. They're probably first generation immigrants; they are probably undocumented for the Latino communities.

Professor D noted:

> They were migrant workers, many of them were members of what we would call day laborers…undocumented laborers…, where they would show up at various locations in town generally near home rehab types of stores and offer their services to work as a laborer in residential areas. Many of them did not speak English or did not speak English fluently.

Initiation of the CBPR Process

Theme 10: Trust is essential in starting a partnership, and preexisting partners facilitate trust. Professor C indicated that she and her academic team have

always been the partnership initiators. She expressed that they would most often request collaboration from pre-existing partners first, since they know which once are "good partners" to work with (with this comment, she implied that there have been instances of bad partnership). Her statement on commitment, due diligence, and good communication was also linked to the above theme:

> It has always been us…We thought about the various organizations who we worked with, and we know the ones that are good partners. You know, when they say they're going to do something, they do it, and they have a good reputation with us, and we have worked with them in the past. And so we contacted them and said we are working on this proposal. This is the idea that we have, and in the case of the name proposal, we were very much, we were very much the convener and the coordinator.

Professor A joined forces with her academic colleagues and sought partnership from the community. Her collaboration with her colleagues was strategic, as her colleagues had access to the community population she wanted to work with and understood and spoke their language. She said:

> My colleague was in the Spanish- Latino community on this project and then I worked in an African American community. So, we initiated it with community members. We approached them about the project, continuing the project.

Professor E said most of the time she initiated the partnership after observing the community clinically; she would engage the community in dialogue around those

observations. All other participants could not remember who initiated the partnership and the process. Some got into the partnership when it had already been formed, according to Professor E:

> It's been 25 years and so I'll have to take a little bit of time to say because it has been mixed. I would say that most of the time, my participation has been through observations that I have had either clinically or about a community and raising specific questions and engaging community members in dialogue around those observations.

Theme 11: Community partners need academic resources (research skills, funding). Resident F and Resident A responded that their community organizations initiated the CBPR partnerships, as they saw a need for the partnerships to help find solutions to issues in their communities. Resident A realized that both his community and academia possessed the kind of resources needed to instill positive social change and justice in his community and so decided to approach the university. Resident A added that in the process of these interviews she recognized that the community members initiating CBPR partnerships also sought academic partnership due to academic relevance and presence in major grant applications and funding. Resident A said:

> So one of the things we said was that we really wanted to bring resources not necessarily financial, but resources….And then that was our goal, our plan was to partner with this one university and have them participate with us in some like-minded CBPR projects where we would be able to

leverage their expertise and they would be able leverage theirs at that point specifically.

Theme 12: Mutual empowerment often occurs during the initiation of partnership. On a positive note, some participants, both community members and academic researchers who expressed positive CBPR outlook, had experienced some empowerment from their CBPR partnerships; although there was not full participation in all aspects of the research in their CBPR partnerships, they experienced positive outcomes. Some academic researchers indicated that they learned the politics and culture of the community agencies with whom they partnered, while community partners expressed that they felt informed about research activities; some indicated that their partnerships with academia provided them with the support they needed to start their own non-for-profit organizations to continue with their wellness programs, to extend benefit to their community.

Professor D, an academic researcher and coordinator of a community-based project, indicated that the community partners and participants in his project benefitted from hands-on training from his research staff, which helped them meet their needs; they were also empowered by being allowed to freely express themselves in their language, which was translated by research staff. Professor D also was able to actually be in the community to personally experience what his participants and partners were going through: “It empowered me to step out of my shoes and into someone else's.” He continued:

> You can form an alliance with those who help to shape that community and those who take leadership there, and you want to give the community an opportunity to have a voice in what you are offering and what you're proposing. And you work together to shape some type of intervention or opportunity that will give a direct benefit to that community…I think for our partners…it was great for them to receive the education, you know. When you have people who have been barely literate in their own countries and their own languages now feel empowered to defend themselves…and for these community agencies to feel like you know we have some people who are official. We were already advocating but we have someone, we have back up now.

Professor C has also seen success in her partnership with community coalition members and has a positive perception of her whole CBPR experience. Both partners and the community have access to the product they jointly worked on:

> I think that the fact that we were able to bring so many people together to develop the healthy guide was a major success. We made that product available to committee members and the people …who participated in the development of the guide. So, they have it and I think that it is definitely going… it will address some of the basic issues you know like around health literacy, diabetes, and cardiovascular disease.

Professor A co-founded a non-profit organization with her previous CBPR partners and study participants. She expressed that she helped them form a new 501c3 organization because she also possessed the skills and expertise in establishing 501c3s, and she also wanted to ensure program sustainability as well as sustain their relationship. Professor A and her academic colleagues serve as advisors for the nonprofit organization to the community members and partners, encouraging them to take ownership of it:

> We are advisors to them. So, they are board members, they make the final decision for their organization. And we are still a partnership in that we still work with them, and we advise them. Our voice is still heard equally. We still feel it's very important that they be on the board, and they make the decisions because this is for their community, this is for them.

Resident D, who is a beneficiary of Professor A's expertise and advice on the 501c3 formation, also had a positive perception of CBPR, as she believed their partnership has empowered them through the formation of their 501c3 organization. She saw the need for continuity of the program and wanted a lasting effect. She also expressed that their lives "drastically improved" after the original partnership:

> Well after the program ended, we the members of the community, we felt that the program was so helpful, so impactful that we didn't want the program to end. So, we collaborated, we the participants collaborated with the research and with groups to ask if we the community participants

> could learn how to keep this program going on our own and so that's pretty much what we have been doing to date…Yea, lives were changed.

Professor F thought it is important that the community is empowered after a research project. He explained that in his partnership he realized that his community partners who may have been shy about expressing themselves improved their public speaking and level of confidence when he gave them leadership roles and recognized their inputs:

> hopefully, that we've had a positive impact on those things (projects). That matters to me. There are other times where that evolves, which can be empowering, where someone is making kind of quiet and not sure of themselves, and once you talk more and more and make them the expert and make them realize the resources and assets that they have, then they build that confidence, and that's excellent.

Resident A expressed his sense of empowerment from his CBPR partnership. He originally had concerns about his academic partner and was "sensitive" throughout the project about making sure the partnership benefitted his community. He said his community members (mostly high school students from a low-income minority community in Chicago who had worked on the project as the frontline community investigators) were empowered when they were given access to the said university to visit the "very executive conference room." When they arrived, the students' pictures were screen savers on computers in the executive conference room, which made them

very excited. He said there is continuity in the program as it has extended to other parts of the city:

> We hired high school students to go out and be scientists or researchers, community-based researchers now this program has an opportunity and is going citywide….So it empowered them to be more open to their community, also to have more dialogue with stores and business owners and to have a method as far as communication and conflict management skills and resolution skills and all those types of things….I also wanted to make sure I had some ownership in developing the research from all ends. So, I participated in all aspects.

Resident E was empowered by the program from the partnership as residents were able to see positive changes in their lifestyles. She looks at the academic researchers as concerned citizens who cared for their well-being and who devoted time for them. These community members became advocates for healthy living in their community, starting with their families:

> Oh absolutely…I think that it was empowering to the community because it was like outreach program. Somebody was out there who cared enough to make you aware ….Before that, it was just like, business as usual and people getting sicker and sicker. But once you were a part of the program, you knew how to eat better, make the time to exercise, and you would also tell your children and your husband….I'd go in to the doctor, didn't ask a lot of questions, and just got out there. But everything out of this

> program, now I ask questions, and I ask for the print outs and results of my blood tests and those kind of things and ask him to explain everything to me and that is a huge difference. So that was very enlightening to me.

Professor B and Professor I expressed that their partnerships have been empowering to the community and to them. Professor B indicated that her research team mentioned that their community partners helped them identify an issue in their original research project design, and so they made some adjustments accordingly. She said that it was a "learning experience" for the researchers and that the project was still at an early phase:

> even going through the process of collaboratively designing, has been a big learning experience for them to say okay we really made some big changes and some big improvements to approach to the study design that we wouldn't have made if we hadn't had perspectives of people.

Community Buy-In Process

Theme 14: Community involvement in identifying the research problem is important. Community support for CBPR or any form of research is critical in recruiting participants for the research or project. It is also particularly important in CBPR as its principles (Israel, 2003) demand full authenticity and equitable partnership in all phases of the research, especially in problem identification and prioritization of community issues. Different academic partners utilize different strategies for acquiring community buy-in in their CBPR projects. A common theme is that academia had to obtain community buy-in through social networking and conversations with community

organizations and community leaders or with someone who knew the target community's leader well.

Theme 15: Cultural familiarity, trust, and alignment with community needs are critical. One theme that immerged was that it was easier to obtain buy-in from a community if the researchers identified themselves as part of that community by race or ethnicity. Accordingly, researchers devised strategies to make this work to their advantage. This rapport brought about trust in the partnership as community partners and members of the community felt comfortable after realizing the research team was culturally prepared and had people who were like them and could understand their culture and language. The buy-in was also facilitated by the need for the service that the research team was going to provide to the community.

Professor A is not Hispanic but needed to work with a Hispanic population for her CBPR study and project, so she identified community health workers from Hispanic communities with help from her Hispanic colleagues:

> The Hispanic/ Latino core, we used community health workers because we started in the Latino community. We used them to be able reach out to members of the community….They have connection to clergy here in Chicago, and we used those connections to be able to tap churches to recruit….We came to the community and said we want to, we at_____, we want to address _____ health disparity. And they were all on board, they wanted to address it because they were on anti-inflammatory every

> day, increasing the over the counter medications, and some of the women actually would get a prescription medication for their joint pain.

Professor I indicated that being an African-American researcher, it was much easier for her to get buy-in from the African American community and churches:

> Because I'm African American and from the community, I was able to identify people whom I knew personally from the respective churches to communicate with and they, in turn, introduced me to the leaders of the church, and then I started telling them about my project. They, in turn, bought into it, and we all agreed and crystalized the topic and the content.

Theme 16: Community representation on an advisory board facilitates research buy-in. Professor B's academic research team and Professor C's team have established a Community Advisory Board where key community members and community organizations are strategically represented and also serve as key informants on research or project topics. These Community Advisory Board members also reach out to their communities to seek approval for research in these communities. Professor B indicated that this is beneficial because the community trusts its own members. Professor B said that she and her team treat these advisory board members with value, honesty, transparency, and respect:

> As the project goes on, different mechanisms are used to reach out more broadly. So, for example, right now, focus groups have been held, and key informant interview have been planned so that is another way of community input not through an organization but more directly. And so

> now, those relationships have been through connections to people who sit on the community advisory board, for the different organizations or associations represented are reached out, also things like, events where groups of or partners that are involved will go to African American based organizations on the south side and be given some time before people are going in, or out from church to share information about it and get people engaged and get feedback that way, so there it's been very positive response.

Theme 17: A well-compensated community research pool encourages community buy-in. Resident F said that her agency serves and already has a trusting relationship with the community, making it easy to recruit participants for their CBPR project from the pool of agency clients. However, Resident F learned that community members resist when they are approached for just information harvesting with no benefit or compensation to them:

> We already have like rapport with our seniors….We already have a pool of community members to choose from. So, our strategy may have been a little different… I did learn that community members can sometimes be very, very, very resistant to research if your approach is to just get information, if you're not giving them something in a sense. Or not necessarily given them something in terms of like money or promising them the world. But if you're not approaching them in a way that makes them feel like they really are included then you get resistance.

Theme 18: Community members tend to resist research redundancies and priority differences. Although all participants indicated that the community supported their research projects, community members did hesitate on some occasions due to differences in problem prioritization, as they felt over-researched already on the topic and wanted an intervention instead. This finding was highlighted by Resident B above, and by Resident C:

> Residents agree, yes we should do research, however, when it came to violence and behavioral health, they felt that is was sort of oversaturated and were a little more concerned about what would be the most effective intervention.…This is one community area, everybody has come in here and researched… I talked to numerous people. And the community members said, 'I understand that you have to come in here and do the research but I'm in a community where people are dying every day, so why are we still researching the cause? The cause is violence, and the cause has to do with aggression and guns. So how do we stop the violence? Understand we know what the cause is, we found out the cause. Can we focus on how to prevent it?"

Partnership/Project Sustainability

Theme 19: Sustainability requires trust, good communication, nurturing, and commitment. Study participants could sustain their partnerships to some level but rarely could sustain the projects or program after funding ended. Some academic researchers and community partners were able to sustain their partnership by establishing

trust throughout the partnership, being clear and realistic from the start of the partnership about goals and roles, and following through with commitment, and being visible at each partner's events to show support, with a view toward upcoming opportunities for partnership. Apart from attending social events, most participants indicated that they maintain some level of communication, mostly through emails and newsletters.

However, maintaining these partnerships was not always easy when project or funding ended, especially for academic researchers, as they had other opportunities to pursue and other priorities. Professor C described her experience after funding ended as "very chaotic." However, she said that when funding ended, it was an opportunity for her and her partners to brainstorm on what they could do next and, as a result, they had a series of meetings. She maintained that, while they did not do a good job in maintaining the relationship, they had lived up to their promise on their previous projects, so trust had already been established; as a result, she was sure her partners would still continue to work with her if other opportunities came up.

> Well that's the thing with the _____ coalition, we have not, probably should, it's been very chaotic year since the funding has ended….I think if we were going to do… if there was another opportunity and we received funding to pick up where we left off with _____, …I think they would continue to work with us because again we lived up to our commitments. We did what we said; we asked them we didn't tell them, and we told the truth. So, you know I think that that was the

> key…cultivate deeper relationships with people and organizations that have been very active and helpful in your collaboration.

Professor B also indicated that maintaining relationships and programs after a project ends is "very challenging" and not really the "job of the researcher," and that "it's ok for partnerships to end" if necessary. Professor B implied that maintaining partnerships should be bidirectional, and that researchers do research and relationship building, and maintenance could be done by staff of representing organizations. She advised that there should be "clarity in the Memorandum of Understanding" about goals from the beginning of the partnership. She experienced problems maintaining partnerships when community organization representatives in the partnerships "turn over," possibly due to a lengthy "gap" in between the projects. However, she also supported visibility at community events and other affordable methods of showing support.

Theme 20: Capacity-building and complete inclusion helps with project ownership by all partners and with sustainability. Professor B advised that the only possibility for project or program sustainability is if everything is inclusive in the original research plan and design, involving and training community members who will continue to run the projects in the community. As she said:

> Sustaining a program is going to be different people than those involved in the research projects, so kind of acknowledging that and being prepared for that and making sure that the right people are at the table for

> the right tasks, and appropriate trainings are incorporated during partnership for community partners.

Professor D expressed that relationships that have been developed and nurtured over time are hard not to maintain, even after funding ends, especially when dealing with populations that are "suffering" or have some type of disparity. Friendships are developed out of these partnerships. He kept communication ongoing through emails, helping them organize, and attending fundraising events. He also did this because he knows "there is always further opportunity for research," and "we like to keep that door open." Professor D indicated that his research team enabled project sustainability for their community partners and participants by empowering and providing appropriate training to their community partners and participants, as explained below*:*

> We helped them realize how they had a responsibility to strengthen the group that they were in by educating each other about these opportunities to work safely and not come home injured. So, I think they went into it as thinking that they could just work for a couple of dollars out of desperation to take care of their families, but they left the program knowing they could protect themselves. They didn't have that initially.

Theme 21: Short-term relationships lead to problems sustaining the programs and partnerships. Resident C, who had not experienced sustainable partnerships or programs in his CBPR experience, described his CBPR experience as a "one shot deal." He supported the idea of sustainable partnerships and programs after funding ends, emphasizing long-term viewpoints and continuity. He tied that possibility

to a relationship that has been properly nurtured throughout the partnership collaboration with the community agency and community members. He also said that partnerships in CBPR must "outlive research funding" because there is always additional opportunity for research funding. He recommended "constant building," "constant communication," "telephone and emails," "going to community events, supporting community events whether it be with time, resources, funding," and "sharing funds." He also indicated the need for research capacity-building for community partners, which could allow them principal investigator privileges and abilities:

> long term, long term, long term (relationships)…I feel that there is some research about that…, I don't like to say it's a one shot deal but it (CBPR partnership) should be ongoing..., providing opportunities for community members to advance their skill sets. Three, develop a pipeline for principle investigators. Now, that's really difficult, but I think that is really great.

Resident B indicated that these "relationships are the backbone to healthy communities," and as such he makes sure that he continuously checks in "with folks from the university" to see what other things are going on. He attends their conferences or sometimes simply has lunch with his university partners. Resident B referred to nurtured relationships as "golden" in CBPR.

Theme 22: Incentives motivate partners for long-term commitment. Professor A responded that her partnership was difficult to maintain after funding ended and so she

had to continue to identify and apply for other funding opportunities. She said people lack commitment at that point since there are no more incentives to motivate them:

> I would say when funding ends, people aren't as committed…of course the funding assisted, got them out every Saturday when we had the program, but yea, I would just say, just say really from this study and that study and my other research, I would say it is more difficult to get people to remain committed when you don't have an incentive anymore, a monetary incentive.

Theme 23. Honesty, respect, due diligence, and acknowledgment are important to project sustainability. Professor F expressed that partnership sustainability depends on what the original relationship was going into the CBPR partnership. For one of his current projects, he had already done a project with his community partners, so they had a positive professional and social history that facilitated the current partnership, project execution, and relationship-building. He still communicated with his partners; however, he did not believe when his current project ends they will be "Facebook friends or anything like that." However, Professor F recommended that in order to maintain a good relationship with partners there should be "honesty on all aspects of the research and partnership from the onset," especially "about what can be done and what cannot be done" and "do what was supposed to be done and do it well."

Professor I described her experience in maintaining the partnership when the project and funding ended: "To be very frank with you, maintaining communication and

relationship with the community after funding expired has been very minimal. It's a time constraint. It's very, very difficult." For program sustainability, Professor I planned to enhance continuity with the community groups she works with, since she has seen the benefits of the projects to the communities. She planned to continue to provide them with professional support after the project ends. However, she said this ongoing professional support:

> It (communication) doesn't have to be every day because the education program is showing to be very vital. people like it and want it, and some of the groups, I understood, are incorporating it into some of their entities. With that being said, the goal is to have an ongoing relationship with the group members, ad infinitum.

Resident D and her community team had established a solid foundation of trust with their academic partners. They still continue to keep in touch with their academic partners, particularly with regard to seeking professional assistance for the 501c3 the academic partners helped them establish. They also called on the academic researchers when they need a speaker or health educator for their current community clients. This was because they wanted the rest of the community to benefit from the same type of experience they had when they partnered with this academic group. As Resident D said:

> Those connecting points have been made over a period of time. It kind of, even now, is a partnership with the current organizers meaning we, the participants, and with the research. Because we are still drawing on their knowledge, we are still tapping into network of speakers. Because we want the same speakers who helped us, to now be able to help others.

Professor E shared the following experience and recommendations for partnership and program sustainability. She said sustainability depends a great deal on the type of relationship established during the partnership, and that partnerships sustain themselves if, "trust, transparency, honesty, shared resources or sharing of information are applied throughout the course of the collaboration, which would lead to the development of a very strong relationship." She also indicated that in her case she provided a capacity-building opportunity to lay community members who were part of her support group. They were trained to serve as "a hybrid model of a peer professional support group leaders," and today one of these peer professional group leaders serves as a Community Health Worker for a direct service provider:

> The person who worked with me was at first the recipient of services through a support group and then later because our project received some funding in order to turn the support group from a professionally led one to a hybrid model of a peer professional support group. This person was able to receive training in order to be one of these peer support group leaders. Fast forwarding over the years, the person is a community health worker with this service organization.

Colearning Experience

Overall, the majority of academic and community participants reported feeling a sense of empowerment through learning during their CBPR partnerships. Some academic researchers indicated that they learned the politics and culture of the community agencies and members with which they partnered. Meanwhile, some community partners

expressed that they felt informed about research activities, and some indicated that their partnership with academia provided them with the support they needed to start their own non-for-profit organizations to continue with their wellness program and to also extend benefit to their community.

Theme 24: Cultural knowledge and education of partners facilitate project priority. Professor D said initially that his research team had categorized their participants under one ethnic group of undocumented workers called Spanish Speakers-Mexicans. However, as the research developed, Professor D realized there were different languages and cultural groups within the population. Accordingly, they had to bring in language translators for all of the language groups. The community partners and participants also learned about their rights as United States laborers through information provided to them by their academic partners. They were also trained by the research staff to provide the same assistance to other community members in need. As Professor D explained:

> What was really unique to learn was that there is an organization that is set up and structured for these Spanish speakers and to help prepare them but that we can't go into this type of research with stereotypical viewpoints. Because we had, yes, a majority of our Latino day laborers who were undocumented were from Mexico but that wasn't the only group. And in dealing with that specifically we did have to deal with the different cultures of the different groups.

Professor A also learned about the culture of her community partners and their major health stressors. In understanding these cultural norms, the researchers could appropriately approach their partners and participants for effective collaboration:

> I heard that African American women give care to their children, their grandchildren, their neighbors' children, and you know, caring for relatives who they call cousins and daughters who aren't technically, biologically their cousins and daughters. So they took care of so many people and they really did put themselves last. And so, in really understanding and hearing about people's stories and who they care for and the load of responsibility really rested on them you know.
>
> In the Hispanic/Latino community, what I learned was that…really how important the husband or the male figure was in their lives and so a lot of them had to get permission from their spouses or significant others to be a part of the program.

Theme 25: Ideally, everyone learns from the strength and expertise of other partners. Professor D indicated that community members tend to learn about research dynamics, while the academic partners learn how to effectively reach out to the community. One strategy that academics used was to train representatives from these communities who had been through the same problems and understood their issues and culture to serve as frontline contacts, not as researchers:

> So, I think they (community partners) were really able to understand the methodology of what case control studies look like and how to make this

> difference and learn from one group versus the other. And really what they taught us was how to get close to this community and not feel like we were violating them by having to ask specific questions. And how it was so important as researchers not to just walk up and present ourselves as researchers but to first train someone from that community, that would be prepared to be able to handle the emotion, and to understand the culture and to be able to present the questions and the format in a way that would benefit the specific community because they had lived there and been a part of the circumstance and had grown from it.

Resident C agreed that there was colearning experienced by community and academic partners during their partnership process. Most importantly, the community partners learned about research, while academic partners learned about the community and why there are hesitations to participate in research:

> Definitely. Yes. There was colearning on both parts. Community members had an opportunity to learn more about the research process, meaning that… just some better understanding of research design and why research is important. But I personally think that the academic researchers learned a little bit more about the population…to help them better understand the reason why some community members are hesitant to participate in research.

Resident B had this to say about the mutual learning experience in his partnership:

> You know, you can always learn even when you know something….You continuously learn, but there is nothing that I can truly pinpoint and say oh that's new or that's fresh, or that's different other than the new technologies that I used to gather and capture this information.

In contrast, Resident F did not learn much during her partnership, "And like I said, in the very beginning, we didn't learn, we didn't know much about any of this so that's why on this partnership, I didn't learn much." Professor E noted a mutual learning experience in her partnership with the community, explaining that bidirectional teaching and learning is one of the principles of CBPR and a requirement for funding. She mentioned that her community partner also took the center stage to make contributions during public discussions:

> It's not just university faculty lecturing to the community, but we bring in community partners who were doing work in the same area and put them on the same stage with university faculty and investigators to talk on the same subject.
>
> Yes, the university investigators who were doing this learned about needs and priorities of community members themselves. And so that was an opportunity for colearning.

Theme 26: Academic achievement does not imply health literacy. Professor A said while her community partners learned from their academic partners about running and managing their own wellness program, she personally learned that just because a person is intelligent, educated, and learned does not mean that person is health literate:

> They would learn from us about how to carry out the program.…One of the participants that has a master's degree, she was the author. She's highly intelligent but she has a low health literacy level and so one of the biggest things I learned was the two were not synonymous, or were not equal.

Theme 27: CBPR requires flexibility, open-mindedness, and receptiveness in all partners. Professor I absolutely agreed that there was a mutual learning experience in her partnership with the community. She learned about the community, which included various faith-based organizations and their associated rules, politics, and hierarchy. She also stated that the community partners were "receptive" to her curiosity. While her community partners learned about the "complexities," "rigors," and the "dynamics" of research process, she did indicate that it was difficult for them to adhere to certain standard research guidelines and to understand that there is very little flexibility once a proposal has been accepted for funding by a funding agency. She also suggested some level of flexibility to facilitate collaboration:

> I learned that we have to be somewhat be flexible in understanding within the parameters of sound research, so that we can adhere to the rigors of what's going on with the churches. And the church leaders, in turn, have to understand similarly the rigors that relate to research, so that the research can be conducted in a scientific manner but at the same time lends itself to the rules and regulations of the respective churches. They also began to understand how difficult it is to recruit.

Resident D said the academic partners learned about some of the root causes of issues faced by the community and that the academic partners came with a mindset to learn about the community and what they had to say in the partnership process as a whole. She described that "…it was an exchange of knowledge." Meanwhile, the community partners and participants learned about the importance of record keeping, data collection, and data fidelity during a research project, as well as the importance of measuring project outcomes:

> Yea, I would say what I came to learn about research was that everything had to be documented and everything had to be written down, had to be recorded, and take notes of it, and so I guess it just made us mindful that we in turn needed to start keeping better track of the issues that were before us so that we could in turn bring them back to the group to share not just with the participants but also with the researchers as well.

Analysis of Themes: Research Question 2

The second research question was the following: What are the levels of participation experienced by participants at each stage in the research process? Nine themes emerged to answer this research question.

Problem Identification and Research Design

Theme 28: The problem is most often defined by the academics. Almost all participants indicated that the problem identification and their research design was done by academic researchers. One academic participant indicated that the problem researched in their partnership was originally

identified by the community agencies they worked with, and they both worked to design the research. The majority of academic participants indicated that their partnerships were collaborative, while the residents reported that the problem and research design were largely identified by academic partners.

Participant Recruitment and Data Collection

Theme 29: Community participants were the main recruiters of participants in their partnership. One academic partner expressed being the main recruiter of research participants. In a few cases, both academic and community partners expressed that they were both involved in recruitment of participants. On some occasions, academic research staff assisted with data collection. Some participants, especially academic participants, indicated that data collection was a "joint effort," as community partners received training from research staff on how to collect the data in their absence. Some community partners expressed that they collected the data, while some academic participants expressed they collected their own data. In some cases, participants in the study collected their own data through daily physical activity and nutrition monitoring.

Data Analysis, Management and Ownership

Theme 30: Residents tend to lack data storage resources and knowledge about data dynamics. Participants expressed that the problem with data management is appropriate storage of said data. Some academic participants complained that community partners do not have the resources for, or knowledge about proper data storage.

According to all participants in this study, “Data analysis, management and ownership were done by academic researchers,” and in a case where the partnership had not reached this level, it would eventually be handled by the academic researcher. Professor D expressed that storage could be a major issue, which explains why the academic partners keep and manage the data:

> I think one thing I may say is that, yes, it would be nice to share it with the community, but where would it be? So, would it be in a library and then we have to deal with city government? We can't necessarily have it at someone's house because you have to deal with confidentiality.

Writing, Authorship, and Dissemination (Publications)

Professors A, B, C, D, and E indicated that they co-authored some form of paper or publication or made a presentation at a conference with their community partners; however, the actual writing was largely performed by the academic researchers. The data in this study indicated that there was not equitable involvement and authorship of the publications or research papers, as expressed by community partners. They indicated that dissemination was done through “public presentation at conferences,” “abstract submission,” or “panel discussions” in most part by both partners according to most academic participants in this study. However, publication of papers was done mostly by academic partners in cases where they got to that level.

Theme 31: CBPR research participants should be acknowledged in publications and be identified in research. Professor F added that the need to

protect the identity of CBPR participants means that they cannot publicly receive the credit they deserve for contributing to positive social changes in their community through research. He would prefer that real names are used in CBPR research to give credit where it is due for contributing to social change. He noted that:

> IRB requirement doesn't provide the opportunity for individuals (participants and informants) to be recognized for their contributions, so if you are going to say 'I want people to be able to choose to use their full name, their true name, and all this, as my consultants or informants, in my project, and to talk about the project they've developed by its name' it will be unethical according to IRB.

Theme 32: Academics believe it is too hard to acknowledge all participants in a publication. Academic participants expressed that there is a problem when the names of all partners and representatives are to be highlighted on the research paper for authorship credit. They said, “There is not enough space for all names,” which usually results in a list comprised mostly of the names of academic research staff, with few or no community partners listed. Professor B also pointed out the issue of having too many authors on a scientific peer-reviewed publication. He said that it may be congested to include the names of all partners and sometimes participants in a study, in which case, the academic researchers being the first and key authors would logically steal the naming spotlight on the papers:

> Now as it is with any paper, there has to be scientific paper, so let's be honest. So one can only have so many authors. So that just again, benefits the academia because you can't have a paper with 300 authors. So that's something that the academic world kind of controls.

Theme 33: Community partners rarely know when partnership research findings are published. Some residents indicated that there were some publications authored by the researchers of participants' lived experience from the programs; however, the residents themselves were not a part of the publications. Some residents also expressed that they were unaware of any research publications resulting from their partnership; Resident D said, "I do know something was published, I don't know or have the name of it, but there was a white paper that was published as a result of our program…" Resident E said:

> My guess is they probably did (a journal article). Now, what I have seen. I did see a film. So there was a film of people talking about their experience on the program. And that is actually on a website right now…

Memorandum of Understanding (MOU) and Definition of Roles and Responsibilities

Theme 34: Early definition of roles and procedures helps prevent conflict and increase commitment. The majority of study participants acknowledged the need for early MOUs or MOUs in general for CBPR partnerships to ensure commitment to roles and responsibilities. They may have

had some form of agreement during the “early stage” of their CBPR research partnership, whereby roles and responsibilities along with other needs were defined; however, because this agreement was not official, there was some deviation in assigned roles and the agreement in general. It was advised that establishing an MOU from the beginning of the partnership, especially during the project proposal, may reduce future chances of misunderstanding and disagreement between partners. For example, Professor C said, “You know, we did not make that (role assignment and agreement) explicit, but what I think is that sharing the work would make things work differently.” Resident F added:

> They (roles) were defined in the beginning. And in that first meeting everybody kind of came together and said, ‘Ok, this is what we will be responsible for, this is what we are asking of you, and that was agreed upon.’ So from the very beginning everybody knew what should have been done. But, yea, not how it panned out.

Professor F also discussed early role assignment:

> I always try to do that [role assignment] very early: 'Here's what we have to offer, here's what we have going on.' Some of that happens organically through the collaborative process. Through conversations, other people will take leads in certain aspects, but again, if it's a partnership, then you have to go not thinking that you're the expert, because you're really not the expert.

Professor B added:

> If you take the time at the beginning to pay attention to the process, potentially set up agreements like memorandum of understanding, or roles and responsibilities, a lot of times those can prevent conflicts from happening down the road or misunderstandings in the communication down the road.

Resource Allocation

Theme 35: Academics have more access to funds and knowledge of grant writing skills. Community members expressed scarcity in financial resources and human capital in their communities and as a result indicated their need for academic researchers' resources. Most academic researchers in this study allocated money in their grant proposal budget for community partner resources --for services, use of space, staff, and office supplies. For community participants in this study, compensation came as a token, human capital, stipend, or nothing at all. It was also mentioned that the community partners do not request compensation in some cases. Professor A stated:

> Yea, so, we did cover the cost of the space on Saturdays…we also covered honorariums for speakers and incentives for participants. Now the incentives that we gave because we were focused on movement, we gave them a pedometer. And I probably shouldn't mention the brand name but we gave them a well know brand name pedometer.

Professor F noted:

> We wrote in 10% for them for just facilitating things, making copies, materials, time, effort on their part -- which is something interesting, they

> didn't ask for that, but as I wrote the grant, and then I made the budget, too, and then I sent it to them as 'what do you guys think about blah?' and got their input back and forth, they never said 'this is too much or too little or exactly right.' They just didn't say anything.

Levels of Involvement

Theme 36. Tokenistic and nonparticipation result from lack of community bargaining efforts. In most cases, participation levels of both community and academic participants in this study for their various CBPR partnerships were inequitable from the viewpoint of the CBPR guiding principles. While all community partners' entities served as the venue for the projects, they helped mostly to recruit participants. Academic partners were involved in the research aspect from design to completion. Outcomes and benefits of the partnerships were also inequitable, non-participatory and tokenistic, as most community partners reported receiving incentives, honorary awards, or nothing at all in return. It was also expressed that the majority of the research publications from partnerships were rarely known by community partners.

Analysis of Themes: Research Question 3

The third research question was the following: What challenges, ethical issues, benefits, and outcomes do participants experience during their CBPR partnership? Eight themes emerged to answer this research question.

Challenges and Barriers

Theme 37: Both academics and community members lack time to commit to partnership. One of the major challenges expressed by both

academic researchers and community partners was the lack of sufficient time to commit to the partnership. With multiple priorities, both groups of participants in this study, particularly the community partners, referred to the lack of time to fully commit to the partnership and project as a major challenge. Professor C mentioned, "We have not done a good job in general communicating with our coalition members as we want to be…", and she said it was due to "lack of time" and time constraints. All other participants expressed "time constraint" as a hindrance to their partnership and commitment.

Theme 38: Difficulties include recruiting and retaining research participants and lack of commitment to partnership. Participants reported that lack of incentives and motivation for the community and community partners could trigger lack of commitment to partnership expectations such as recruitment and retention of study participants, which is usually a task assigned to community partners. Moreover, lack of funding could trigger lack of commitment from academic researchers. Resident F noted:

> Folks in our community like to be compensated for their time and effort. When there is nothing to encourage them with to participate, they show up once and may not show up throughout the required number of times needed by the research. Sometimes they rush their response to surveys just to get done with them

Theme 39: Following textbook research dynamics and lack of community research capacity are challenging. Most academic researchers

expressed that the process of CBPR is lengthy, especially when trying to establish trust with the community and that the textbook CBPR principles are mostly unrealistic to follow verbatim. Some academic researchers said understanding and following through with research expectations was also a challenge for most community partners and "slowed down" the process, requiring community training from academic staff and researchers. This challenge also could result in potential data inaccuracies and distraction from research protocols.

Theme 40: The difference in organizational priorities was a challenge in partnership commitment. Most participants mentioned that different priorities could hinder successful CBPR partnership as organizations, particularly the community organizations, may have multiple urgent priorities that are contrary to those of academic researchers. They said it could slow down progress towards partnership goals. Other common challenges expressed by participants in the study included working through conflict resolution, making data ownership decisions, sharing financial resources, sustaining the partnership after funding ends, obtaining community research buy-ins, trust building, respecting MOUs, IRB requirements, retaining their control from academia, ensuring multiple authors on research publications, making the commitment, and having difficulty following CBPR textbook principles.

Ethical Issues (IRB)

Theme 41: Strict IRB demands can slow down partnership progress. Some academic participants indicated that the process and length of time required by the IRB posed as ethical issue. Professor F explained his frustration sarcastically below in reference to his initial partnership interactions with his potential partners and his university IRB:

> Can you wait three months while I get IRB clearance?' and then they say, 'Sure.' And then you get it and you go there and you say, 'Okay, here's what they said,' and then they say, 'Yeah, but we like to recruit people this way.' And then you say, 'Okay. Well, can you wait another month and a half while I get the IRB amendment?' Not to totally bash the IRB, but things move at a different pace, so…

Theme 42: IRB requirements do not represent the needs of the community. Professor F further discussed the issue of IRB for CBPR as it relates to the types of questions IRBs ask. He thought the questions on the IRB forms do not make sense, and that the community partners do not care about them. He also further mentioned that academic researchers quite often write approvable consents for quick approval but would harmlessly not abide by the rules stated on the IRB:

> The questions asked don't make sense when it comes to: are you going to treat these people with respect? Are they going to feel valued? Are they truly your partners? Are you truly collaborative? Is this mutually beneficial? They don't care about any of that, so

> in that case, yes, we had an IRB, but we all know what's going to be important -- we all know how to jump through the IRB hoops and to write informed consent that they'll approve, and then you do what you're going to do on the ground. That doesn't violate anything you say, but it's intentionally vague.

Professor F recommended that the IRB requirements for social science research (such as CBPR) should differ from those that apply to traditional biomedical research, as he thought both address different types of concerns. With a mindset that IRB is bureaucratic, Professor F posed some questions on the relevance of IRB in relation to CBPR:

> If we're agreeing that the IRB protects participants, then, yes, we should have one that is defined to address the types of questions and concerns that are likely to come up in CBPR. If we agree that the IRB becomes overly bureaucratic and is an impediment to doing good work, then no, we shouldn't have more of it. But if we're going to have it -- which we're going to have it -- then yes, there should be someone in the room when you say, 'Here's what I'm doing,' and they all look at each other and say, 'Is that okay?' and then someone says, 'Well, it doesn't go against any rules that we have, so yes, it's okay.'

Theme 43: Evaluation measures that apply to CBPR are needed. Professor E also expressed similar concerns about the rules and requirements of IRB as they relate to CBPR, community-engaged research, and patient-centered outcome research. She

inferred that although the Belmont guidelines for ethics in biomedical research protect the subjects during research, they are misplaced and should be apropos to CBPR guiding principles. She suggested that the principles of CBPR should be highlighted during grant reviews for proposals and should be evaluated for whether or not investigators have satisfied the criteria for community-engaged and CBPR-type of research:

> And it's just, I'm thinking about the burden and also whether or not by turning it into a procedural exercise whether or not it will become meaningless. In that, that is not the place you need to have it. You need to have it in the hands of the people who are reviewing the grants in enough detail so as that particular proposal is being evaluated whether or not the investigator has satisfied the criteria for whether or not it is community engaged research.

Summary of Themes: Research Question 1

RQ1: What are the perceptions of academic researchers and low-income community members about their experience of the process of CBPR, before, during, and after their partnership?

Perceptions and Knowledge of CBPR

Theme 1. CBPR is research where academics get access to community experience.

Theme 2. CBPR can be collaborative, with good community engagement.

Theme 3. Research has to benefit all partners.

Theme 4. Community trust towards university researchers has to be earned.

Theme 5. Participatory programs and partnerships tend to lack sustainability.

Theme 6. Research dynamics and IRB requirements can be challenging.

Theme 7. Community members may lack power, and academics may intimidate them.

Theme 8. Affected communities face limited resources as well as poor health.

Theme 9. Language barriers and lack of documentation hinder communication

Initiation Process

Theme 10. Trust and preexisting relationships are essential when starting a partnership.

Theme 11. Community partners need academic resources (research skill, funding).

Theme 12. Mutual empowerment often occurs during the initiation of partnership.

Community Buy-In

Theme 13. Community involvement in identifying the research problem is important.

Theme 14. Cultural familiarity, trust and alignment with community needs are key.

Theme 15. Community representation on an advisory board facilitates buy-in.

Theme 16. A well-compensated community research pool encourages buy-in.

Theme 17. Community members resist research redundancies and priority differences.

Partnership/Project Sustainability

Theme 18. Sustainability requires trust, good communication and commitment.

Theme 19. Capacity-building and inclusion promote ownership by all and sustainability.

Theme 20. Short-term relationships lead to problems sustaining programs/partnerships.

Theme 21. Incentives motivate partners for long-term commitment.

Theme 22. Honesty, respect, due diligence, and acknowledgment are keys to project sustainability.

Colearning Experience

Theme 23. Cultural knowledge and education of partners facilitate project priorities.

Theme 24. Ideally everyone learns from the strengths and expertise of other partners.

Theme 25. Academic achievement does not imply health literacy.

Theme 26. Understanding cultural norms and their links to health enhances programs.

Theme 27. Partners learn current and new terminologies and subject matter literature.

Theme 28. Research dynamics and community politics are complex.

Theme 29. Smooth long-term collaboration requires flexibility and open-mindedness.

Summary of Themes: Research Question 2

RQ2: What are the levels of participation experienced by participants at each stage in the research process?

Problem Identification and Research Design

Theme 30. The problem is most often defined and designed by the academics.

Theme 31. Community partners were the main recruiters of their study participants.

Theme 32. Residents lack data storage resources and knowledge about data dynamics.

Writing, Authorship, and Dissemination

Theme 33. CBPR research participants should be acknowledged in publications.

Theme 34. Academics find it is too hard to acknowledge all participants in a publication.

Theme 35. Community rarely knows when partnership research findings are published.

Memorandum of Understanding (MOU) and Definition of Roles

Theme 36. Early agreement on roles and procedures helps prevent conflict.

Resource Allocation

Theme 37. Academics have more access to funds and knowledge of grant writing.

Levels of Involvement

Theme 38. Tokenistic nonparticipation results from lack of community bargaining.

Summary of Themes: Research Question 3

RQ3: What challenges, ethical issues, benefits and outcomes do participants experience during their CBPR partnership?

Challenges and Barriers

Theme 39. Academics and community partners lack time to commit to partnership.

Theme 40. Difficulties include recruiting/retaining participants and lack of commitment.

Theme 41. Following textbook CBPR is challenging given lack of community capacity.

Theme 42. Differences in organizational priorities challenges partnership commitment.

Ethical Issues (IRB)

Theme 43. Strict IRB demands can slow down CBPR partnership progress.

Theme 44. IRB requirements do not represent the needs of the community.

Theme 45. Questions focus on traditional research instead of CBPR approach.

Theme 46. Evaluation measures applying to CBPR are needed.

Themes revealed by the participants' comments showed that the use of the CBPR approach to partnership and health promotion is still a fit approach for that purpose, although they expressed some challenges in this form of partnership. For example, regarding the initiation process, the academic researchers approached the community members for CBPR partnership most of

the time, usually through networking events, although they sometimes budded from pre-existing collaborations. In one situation, the community member approached the academic researcher for a CBPR partnership that would create and measure innovative ways to enhance their community's development.

Most participants agreed that their partnership was beneficial to them and that there was a mutual learning experience that yielded positive outcomes. However, participants' knowledge and perceptions of CBPR were different and a bit far from the true definition of CBPR. The academic participants understood the definition and the essence of the CBPR approach to research partnership, while most community participants were vague in their definition and knowledge of CBPR. However, most participants understood that CBPR is a collaborative, bi-directional beneficial partnership. The description "equitable" partnership was rarely utilized by either academic researchers or community participants.

This lack of knowledge about the equitability of CBPR partnership raised themes such as lack of shared governance in the partnership stages and procedures, lack of funding resources, and unequal access by community partners to grant budget monies, which left the community partners powerless. It could also be argued that this same issue of inequality in partnership procedures and benefits has left the community in distrust of academic researchers, given the minimal benefits, lack of sustainable outcomes, and lack community relationship nurturing from academic researchers. Trust, which was expressed by all

participants to be a major factor in initiating and maintaining a successful CBPR partnership, was highlighted by most community participants as being lacking. The data also revealed that participants, especially community members, wanted more voice in the decisions related to their CBPR partnership from the planning stages through implementation and evaluation; they want the needs of the community to be lead research objectives. They want to be well represented and compensated. They want programs and partnerships that are beneficial to the community and that last longer. They want to learn how to sustain the programs in the community. They want partners who understand their culture. As a framework for these desires, they demand due diligence, true commitment, true partnership, and most importantly, to be respected in the process.

Meanwhile academic researchers in this study also understand the importance of respect, due diligence, and sustainable programs; however, they find themselves trapped by other emergent demands from academia and lack time to fully commit to long-term relationships, especially when funding ends. Most often, the tendency of researchers may be to focus on topics where there is funding availability, as well as pressing academic demands for publishing research as an obligation for tenure promotions. This could lead to distractions from the focus on action-oriented research and the sustenance of partnerships deemed unimportant at that point in time. Some academic researchers also advocated for reasonable and appropriate IRB requirements and less complex

research dynamics for CBPR partnerships, with evaluation of the use of CBPR principles as a measuring tool for successful CBPR partnership.

The themes identified highlighted the need for greater educational awareness about the principles of CBPR and authentic, equitable CBPR partnerships among some Chicago community organizations. All of them knew the term community based participatory research (CBPR); however, not all community participants understood the depth of CBPR, implementation requirements, the extent of benefit when applied authentically, or how much bargaining power they could have for their community and agencies in such partnerships if they were more knowledgeable about CBPR. Sustaining partnerships and programs was one of the major concerns for both academic researchers and community participants. Although these disparities existed, some of the interviews revealed success stories in their project outcomes and partnerships.

Chapter 5 follows with interpretations and conclusions. The results of this study can be used to strengthen educational awareness and reinforcement of the principles of the CBPR approach to research, thus improving future health outcomes for those involved. They might also be used to minimize unnecessary expenditures on inappropriately, non-culturally tailored planned, designed and implemented public health interventions. The results of this study have been used by this researcher to develop a new framework for successful CBPR practice, which includes education, equitable participation and benefit, long-term

commitment, and CBPR partnership evaluation, as will be described in Chapter 5.

Chapter 5: Interpretations, Recommendation, Summary and Conclusions

I examined the perspectives and lived experiences of community and academic CBPR partners regarding the application of CBPR guiding principles, the different levels of involvement, the unmet challenges they had experienced, and recommendations for best practices. I also assessed the extent to which academic research institutions through their ethics committees (IRBs) ensure that they are protecting not only the interests of research participants but also those of the communities to which these research participants belong.

Themes revealed by the participants' responses showed that the use of CBPR is appropriate for partnership and health promotion, although participants reported some challenges regarding this form of partnership. For example, regarding the initiation process, the academic researchers approached the community members for CBPR partnership most of the time, usually through networking events, although partnerships sometimes emerged from preexisting collaborations. In one situation, the community member approached the academic researcher for a CBPR partnership to create and measure innovative ways to enhance the community's development.

Most participants agreed that their partnership was beneficial to them and that there was a mutual learning experience that yielded positive outcomes. However, participants' knowledge and perceptions of CBPR were different and a bit far from the stated definition of CBPR (Kellogg, 2016). The academic participants understood the definition and the essence of the CBPR approach, while most community participants

were vague in their definition and knowledge of CBPR. However, most participants understood that CBPR is a collaborative, bidirectional, beneficial partnership. The term *equitable* was rarely used by either academic researchers or community participants.

This lack of knowledge about the equitability of CBPR partnership was reflected in themes such as lack of shared governance in the partnership stages and procedures, lack of funding resources, and unequal access by community partners to grant budget monies, which left the community partners powerless. It could also be argued that this issue of inequality in partnership procedures has left the community in distrust of academic researchers by providing minimal benefits, lack of sustainable outcomes, and lack of community relationship nurturing from academic researchers. Trust, which was expressed by all participants to be a major factor in initiating and maintaining a successful CBPR partnership, was highlighted by most community participants as being lacking.

The data also revealed that participants, especially community members, wanted more voice in the decisions related to their CBPR partnership. From the planning stages through implementation and evaluation, they wanted the needs of the community to be lead research objectives. They wanted to be well represented and compensated. They wanted programs and partnerships that would be beneficial to the community and that would last longer. They wanted to learn how to sustain the programs in the community. They wanted partners who understood their culture, related to them diligently, and demonstrated true commitment, authentic partnership, and respect.

Academic researchers in this study understood the importance of respect, due diligence, and sustainable programs; however, they reported that they found themselves trapped by other emergent demands from academia and lacked time to fully commit to long-term relationships, especially when funding ended. Most often, the tendency of researchers was to focus on topics where there was funding available, as well as pressing academic demands for publishing research as an obligation for tenure promotions. This may have led to distractions from the focus on action-oriented research and the sustenance of partnerships deemed unimportant at that point in time. Some academic researchers also advocated for reasonable and appropriate IRB requirements and less complex research dynamics for CBPR partnerships, with evaluation of the use of CBPR principles as a measuring tool for successful CBPR partnership.

Identified themes also indicated the need for greater educational awareness of the principles of CBPR and authentic, equitable CBPR partnerships among community organizations. All participants knew the term community-based participatory research (CBPR); however, not all community participants understood the depth of CBPR, the implementation requirements, the extent of benefits when applied authentically, or how much bargaining power they could have for their communities and agencies if they were more knowledgeable about CBPR. Sustaining partnerships and programs was one of the major concerns for both academic researchers and community participants. Although these disparities existed, some of the interviews revealed success stories in their project outcomes and partnerships.

Results indicated that both community and academic participants understood the importance of collaborative efforts in CBPR partnerships and the need to build on strengths of each partner. This finding is consistent with CBPR principles (Schulz et al., 1997), as highlighted by academic participants during the interviews. However, both academics and community members thought that the other benefited more from their partnership. Moreover, most academic participants understood the importance of empowering their community partners to take the driver's seat on the projects that affect them while encouraging colearning and capacity building. Academic participants seemed to be more concerned with the level of commitment of community partners in their projects and expressed that by fully engaging and empowering their community partners, they could instill in them the need to take ownership of the projects, which may enhance their commitment to the projects, leading to increased sustainability.

Interpretation of Findings

Knowledge of CBPR and Consistency with CBPR Principles

CBPR is a form of research not commonly known, practiced, and encouraged in most higher education institutions (Israel et al., 1998; Israel, Schulz et al., 2001; Nyden, 2003). However, research funding agencies are now emphasizing the application of the CBPR method of research and intervention, making CBPR a more popular approach among academic researchers in pursuit of research funding. In essence, CBPR is a form of research involving equitable input and equitable benefits from partners involved, meaning that all partners are involved in all phases and benefit from all aspects of the research. Although some participants in this study reported successful outcomes in their

CBPR partnership, consistency in the CBPR guiding principles was not reported by all academic researchers and community partners. The academic participants were more knowledgeable about CBPR, whereas the community participants had less in-depth knowledge of CBPR and could not fully understand whether their CBPR partnerships were in conformity with the guiding principles of CBPR. Participants were involved in different types of collaborative research, mostly community-based research not necessarily conducted with equitable input from the community but conducted in the community; this was also seen in Seifer's (2006) evaluation of CBPR partnerships/projects and Jagosh et al.'s (2011) systematic reviews of CBPR partnerships and programs/projects. Often researchers and community members use the term CBPR to describe their research project in the community, when it is community-based research conducted in the community not necessarily with the community input and without authentic CBPR partnership.

Participants in this study understood that CBPR is a collaborative form of research partnership; however, the degree of participation was unknown to most community participants, and they did not know how far that collaboration should extend. Perhaps they followed what their academic research partners told them should happen. This lack of in-depth knowledge of what authentic CBPR is and its guiding principles could also be interpreted as one of the reasons why community health interventions may not yield long-term benefits (Anderson et al., 2012). Community participants may not realize how much bargaining power they may exert throughout all phases of their partnerships, which could lead to enhanced sustainability of partnerships.

A common trend relating to inequitable partnerships is that the academic partners initiate CBPR partnerships and are the research experts, while community partners and members are mostly involved in events and research problems that are primarily planned and initiated by their academic partners (Anderson et al., 2012; Brown et al., 2010; Flicker et al., 2007). In this study, the academic partners reported that they handled the research design, data collection, data analysis, data management, data ownership, publications and authorship, and dissemination of research aspects of the partnership, while the community partners mostly served as the venue for the research and the recruiters and retainers of participants. A need for community research capacity building emerged from this inequitable research involvement, which was also emphasized by the guiding principles of CBPR.

If the CBPR principle of building on the strength of partners is applied in the cases in this study, it could be argued that these in contributions in the partnership make it equitable, as all participants contributed what they could to the partnership. However, the CBPR idea of research capacity building for community partners would underscore that argument, as its emphasis is also on equitable involvement of all partners in all phases of the research, and that could be achieved only through training the community in research

Research capacity building was lacking in most of the partnerships as expressed by participants of this study, which was also reflected in the literature (Rosenthal et al., 2014). The need for additional research capacity building for community partners was

emphasized in their recommendations, as was more community education about the strengths of authentic CBPR and its empowering opportunities.

Results showed that participants understood what CBPR is about, and they placed emphasis on the collaborative nature of CBPR and the need for research to benefit all partners. However, community partners indicated a lack of sustainability in projects, a lack of trust for university researchers, and an air of intimidation from university officials. However, I have not seen study findings indicating university intimidation of community partners in matters related to research. The perception of university intimidation from the community may be a feeling and not a reality as researchers may not be aware of these feelings from the community. This could easily be resolved through open dialogue among partners and full community engagement, establishing a sense of ownership for all partners from the start of the partnerships until the end.

Initiation Process

It takes some level of trust to initiate a CBPR partnership as expressed by participants in this study, and the process of initiation is most often started by university researchers. As confirmed in the literature (D'Alonzo, 2010), partnership initiation is a wooing process to build a required amount of trust, and this takes time, commitment, nurturing, and honesty. Some community organizations seek the expertise of university researchers by initiating partnership to achieve organizational goals, to obtain funding for their projects, and to obtain help in designing and implementing the projects. The most needed resources by community partners are researchers' capacity in designing and evaluating programs and projects.

Community Buy-In

The issue of trust is also highlighted in this study's findings as it relates to community buy-in from university researchers. Given the preestablished negative perceptions about university researchers and research redundancies, the art of researching the same issues in the same communities over and over again by different researchers, it may be challenging to obtain community research buy-in as they may be feeling over-researched. Financial compensation or tokens to the community sometimes facilitate community buy-in in research partnership and participation. With compensation and tokens, community organizations are more at ease with introducing the research idea to their communities and members, leaving them with a sense of win-win for participating in the research.

Partnership/Project Sustainability

Long-term commitment to partnership goals and partnership and program existence results from nurturing relationships with good communication, honesty, mutual respect, due diligence, and capacity building. A bidirectional benefit for both partners, incentives for community participants, and equitable involvement in all phases of the partnership and projects by all partners are also highlighted in this study and in literature (Seifer, 2006) as a motivation for full commitment to partnership.

Colearning Experience

Results of this study showed that there were colearning experiences for most participants in their CBPR partnerships, one of the major expectations of CBPR partnerships; however, the levels of empowerment or learning cannot be measured in this

study and can be viewed mostly in relation to basic learning of common phenomenon in CBPR partnerships. Whereas participants claimed to have learned or have been empowered in their partnerships, it could be argued that research related capacity and knowledge is vaguely is rare with community participants in this study There was no thorough research capacity building and training for the community partners to the point where they might be self-reliant in research; they mostly learned basic research skills.

University researchers claimed to have learned about the community and politics of community organizations. Again, this is a notion that is vaguely expressed. It could be argued that knowing about the community and its politics does not really mean understanding their cultural dynamics. However, some university researchers saw the importance of understanding the community's cultural norms in designing and implementing successful programs.

Problem Identification, Research Designs, Authorship and Dissemination

As confirmed by literature, university researchers took the lead on identifying the research problems as well as designing the research. The same goes for writing research manuscripts and authorship of the research publications. University participants indicated over crowded authorship on research publications if they have to include the names of all members in their partnerships on the publications. It is common observation that the community partners lack research capacity and most often abandon these roles to their university partners, who also have great interest in this aspect of the partnership, in conformity with academic ranking requirements. Besides, university researchers are more thoroughly trained for research than community partners, although some community

partners may have experience in academia and research as one of this study's participants.

Generally, community partners lack the capacity to also manage and store data from their study, making it easier for their university partners to take the research lead. Usually, because of the lack of research capacity and research interest, some community partners may not be aware of publications resulting from their partnership. They most often realize it during dissemination when their university partners present at conferences or present findings to them.

Memorandum of Understanding

The issue of lack of full commitment from community partners was raised by academic participants, an issue which is mostly a result of mismatched priorities in organizational goals as seen in literature. Most often the community partners or organizations have defined sets of primary services they render on a daily basis to their clients, making their partnership with university researchers secondary in all aspects. Because of that, participants in this study raised the point of view that with early establishment of a Memorandum of Understanding (MOU), clearly defining roles and responsibilities, partners would be able to fully commit to their various obligations until the end of the project. They also indicated that a MOU would prevent conflict during the partnerships.

Resource Allocation

Most academic researchers in this study responded to allocating money for resources in the budget for community partners in their CBPR grant proposal for services, use of their space, staff and office supplies. For community participants in this study, compensation came as a token, human capital, stipend, or nothing at all. Community participants indicated that they lacked resources and that their university partners have easier access to funding. This is because university researchers are more skilled in research and grant applications than community partners. The issue of equal or reasonable access to funding money by all partners is also raised as university researchers usually have access to more of the research funding money than their community partners.

This issue can be argued by university partners that it all depends on the funding sources and funding requirements as there are different requirements for different funding. Most often research funding may not include service funding. There are logistic requirements and benefits from a university which must be met when a grant is funded through the university. However, this issue could be resolved by educating funding agencies on these details so that their requirements and funding would be all inclusive for both partners.

Levels of Participation

Per Arnstein's ladder of citizen participation (1969), there are three major categories defining levels of partnership involvements in research or projects:

Citizen power. This refers to situations in which community members control or are real partners in the decision-making that constitutes the research process. This is considered the most authentic participation. This level was rare for participants in this study. Participants indicated a lack of full commitment at some point in their partnerships that could be attributed to several reasons. As previously explained, most community partners as confirmed by literature, had different priorities from their academic partners, causing some lack of vested efforts from community partners. This is a result of the fact that community agencies are mostly service-based entities which exist most often to provide specific services to the community or their clients. Incorporation of research and its whole dynamics into their daily activities was considered a drag to their daily activities. Moreover, most community participants expressed that university researchers are not fully vested in the community and do not always engage the community in their research except when they need research participants for their data. Some academic participants in this study indicated that long-term commitment to the community is a challenge after research funding ends and besides they too have other priorities and obligations to fulfill as academicians. To some extent, both sides brought some reasonable points, but for the purpose of CBPR partnership and its guiding principles, it is important for both sides to be fully committed from start to finish to enhance or enable sustainability.

From the above argument, it can be concluded that community partners should take more ownership of their partnership and projects, while the university partners make concerted efforts to fully engage the community, long term with training for research

capacity. For these reasons, recommendations were made by both partners on how to carry on a successful CBPR partnership. It must be noted that the Arnstein's (1969) ladder of citizenship participation has been used only in social work but not in the field of public health as a guide as a way to assess the extent to which projects reported as CBPR actually practice the principles of 'community participation'. This research study used this as an innovative method to classify authenticity in CBPR partnerships and collaborations. This researcher thought that a combination of CBPR guiding principles, ladder of citizenship participation and CACT could serve as a way to assess the extent to which projects reported as CBPR actually practice the principles of community participation and enhance success in CBPR partnerships.

Tokenism. This is a lesser degree of citizen participation than citizen power. At this level of participation, citizens are not fully engaged in the partnership and research, although they are claimed to be; however, they are given a little token at the end of the research (e.g., a recognition award, minimum compensation). Sometimes the community partner may be invited to be a board member on the research team but will have little or no power amid all the researchers. This situation described most of the experiences of community participants in this study whereby some academic institutions invite community partners on their institutional advisory boards, granting them a voice in the decisions related to campus-community collaboration and research/project/programs. Some other community participants in this study were awarded a stipend for their time as compensation, while some were compensated for the use of their space during their partnership period.

Nonparticipation. This refers to situations in which the community is informed or consulted but has limited control. Nonparticipation is characterized by situations in which the community is said to benefit but in fact is manipulated and has no control at all. There were cases like this in this study where community partners simply served as a research location and not as CBPR partners. Most community partners were not involved in the different stages of research, except when it came to recruiting and retaining research participants for their partnership research.

The majority of partnerships examined in this study were described by the participants in terms of tokenism in which the community partners were involved in some phases of the research and were compensated in some way, usually through a stipend, board membership, or human capital assistance, but they did not play a significant role in the more fundamental aspects of the research (i.e. defining the problem, selecting the data to be collected, and managing and interpreting the data) (Brown et al., 2010). The majority of community partners in this study were involved in or facilitated the recruitment and retention of study participants in their partnership research and also served as venue for data collection in the community. A few community participants indicated that they took part in data collection and also in their research dissemination. Majority of university participants agreed to the above points as they indicated lack of research commitment from the community and lack of research capacity from the community. Adequately training the community to fully adhere to research dynamics was a challenge to university researchers who indicated that it is a process that should be long term for complete learning. Some academic researchers in this study indicated instances

that might be considered examples of citizen power, but no such instances were mentioned by community participants. In no case did the community have equal power with academics in research decisions.

It should be noted that some of the study participants had not reached the end of their CBPR partnerships at the time of the interviews, and as such were unable to indicate whether the end products of the partnership (interventions and in most cases research publications) were equitably beneficial. However, available data did indicate that partnership equality did not exist, as the focus of this study was on the CBPR principles application. The partnerships could have been appropriate if their study focus was on traditional biomedical and other forms of collaborative research.

Ethical issues and concerns. A major ethical issue raised was the content of the Belmont report research guidelines on the IRB (Flicker et al., 2007; HHS, 2013; Jagosh et al., 2011; Shore et al., 2015; NCPHBBR, 1979), which does not truly protect the community partners and as such does not suit CBPR. Some participants suggested the need for a CBPR-specific IRB to protect the interests of community partners, with emphasis on adherence of the principles of CBPR. There was also an implication that the process of CBPR is extensive, and it is difficult to follow the textbook requirements of CBPR. This also leads to the challenge of adherence to research dynamics, as expressed mostly by academic partners concerning their community partners.

Based on the results of this study, the researcher picked up instances of ethical concerns as they relate to IRB requirements and conformity with the principles of CBPR. Partnership equality was not pervasive, as a majority of the tasks were led and owned by

academic partners. Although most participants reported successful partnership and project outcomes, the researcher still had to consider these successes in the context of the guiding principles of CBPR, levels of involvement, and aspects of CACT in the partnerships. Moreover, most academic participants raised the issue of lengthy and demanding IRB requirements in research. They perceived the IRB procedures and requirements to be made for traditional biomedical research and not fully relevant to CBPR type of research, and as such recommended a special type of IRB requirements for CBPR partnerships and projects. Based on the study findings, the success factors, barriers and challenges, and recommendations made by participants and in the literature, the researcher has developed a framework for sustainable CBPR partnerships and programs or projects.

Barriers and Challenges

Participants in this study expressed several barriers and challenges in their CBPR projects and partnerships that were mentioned in the literature. Challenges relating to project and partnership sustainability when funding ends was emphasized by all participants. Major barriers to project and partnership sustainability included difficulties obtaining funding and other relevant resources. It could also be deduced that these afore-mentioned challenges relate to the challenges community partners face while writing grants as well as to their lack of research capacity and knowledge.

The challenges of conflict resolution were mentioned and, also connected to barriers such as differences in project priority between researchers and community partners, respect for the Memorandum of Understanding, decisions regarding data

ownership, sharing of financial resources obtained through grant funding, and commitment to partnership priorities. Other challenges expressed related to the research aspect of the CBPR partnerships. These challenges included recruiting research participants, retaining research participants, obtaining community research support, building trust, CBPR process longevity, and lack of research capacity; these challenges are also identified in the literature (Mason et al., 2013).

This study presented some new barriers and challenges faced by participants in their CBPR partnership. These included lengthy IRB requirements, maintaining control from academia by community partners, respect of research dynamics by community, multiple authorship on research publication, difficulty following CBPR textbook principles, and difficulties following and respecting MOUs and defined roles. Based on these challenges, it could be argued that participants presented a need for research capacity building, community bargaining power in CBPR partnerships, ownership of projects/programs by community members, strong emphasis on equitable division of grant resources between academic and community partners, and educating funding agencies about the need for these types of equitable division.

Theoretical Considerations

Data from this study indicated a need for sustainable projects/programs and partnerships within the community. Almost all other elements of the CACT are demonstrated by the results of this study, except for the element of project and partnership sustainability after funding ends, an affirmation made also indicated on the principles of CBPR emphasizing long-term relationship and partnership, even after

funding ends as a success factor and one of the requirements for authentic CBPR practice (Schultz, 1997). This aspect of the CBPR partnership is highly critical if research partners seek true social change in the communities in which they serve. Social change and justice require long-term commitment to see noticeable changes through evaluation and observation. Therefore, it is important to ensure research and project capacity-building as well as sufficient funding for long-term commitment to the goals of the CBPR partnerships.

The community action coalition theory (CACT) (Butterfoss & Kegler, 2002), which has been used to build community agreement among diverse individuals and organizations in partnership to address community issues, was used to inform this study. The CACT provides a framework for examining the processes of partnership building, shared governance and the outcomes of projects. A focal point of interest in the theory is promotion of long-term commitment among partners even after project is executed, to ensure continuity, functioning, building partnership synergy, and establishment of community and organizational change (Butterfoss & Kegler, 2002).

The CACT model in this study provided an underlying framework for clarity on the process and results experienced by effective and authentic community coalitions in addressing intermediate and long-term health outcomes. Community partners as well as the academic researchers were also asked to answer questions relating to the application of CBPR principles laid down by Israel et al. (2003) in conducting CBPR collaborative research as a tool for assessing critical elements of community participation in their partnerships and also to inform various challenges experienced during their research

process and partnerships. Arnstein's degree of participation classification (1969) was also utilized - to assess the degrees of participation by partners in the CBPR projects. In Arnstein's 1969 ladder of citizen participation described as eight steps on (see Figure 3). She described the most authentic participation citizen power, followed by tokenism, which refers to situations in which the community is informed or consulted and often given a token, but has limited control. Nonparticipation is characterized by situations in which the community is said to benefit but in fact is manipulated and has no control at all over the research or partnership and hardly any benefit.

Proposed Recommendations for Practice

In all the above-mentioned frameworks, none of them highlight the need for evaluating and assessing participatory partnerships for authenticity. When any programs and partnerships are assessed and evaluated, there is likelihood to right the wrongs that existed, creating room for improvement in all aspects assessed. These improvements are also likely to enhance longevity in the programs and partnerships even after funding ends as there are always other funding opportunities.

The results of this study in combination with some literature recommendations (Jagosh et al., 2011; Stacciarini et al., 2010) indicate a need for another framework for sustainable CBPR projects and partnerships with observable equity in governance and outcome benefit. The data have been used to develop a new framework (see Figure 5), called "Must Agree First Then Must Commit" (MAFTMC). It is a framework that

requires there be a mandatory agreement from the very beginning of the CBPR partnership to identify and assign roles and responsibilities with an emphasis on policy adherence. This form of agreement would require that possible issues related to the CBPR partnerships and initiatives be identified, discussed, and resolved before the project begins with regular times to return to discuss new situations. It is important that the emphasis be on educating community partners about the guiding principles of CBPR and research capacity-building in general prior to project initiation. University partners should also be well informed and educated from the start of their partnerships about the communities they would be working, with the help of their community partners informing them about local perceptions of availability of local research participants, their skills, administrative and financial needs.

It is important that the CBPR partnerships offer opportunities for bi-directional learning. The agreement would require that roles and responsibilities be identified and assigned per available human capital and expertise. It would also require that partners commit to their agreed and assigned duties until the established end of the project. Efforts for obtaining other funding opportunities after current funding ends should accompany the whole partnership process to increase chances for program/project continuity. It also seems that when each member commits and owns their partnership responsibilities, there is potential for sustainable and equitable outcome benefit with a possibility of equitable governance. Following is this researcher's proposed framework for sustainable

CBPR partnership with consideration of input from this study participants and literature on CBPR challenges:

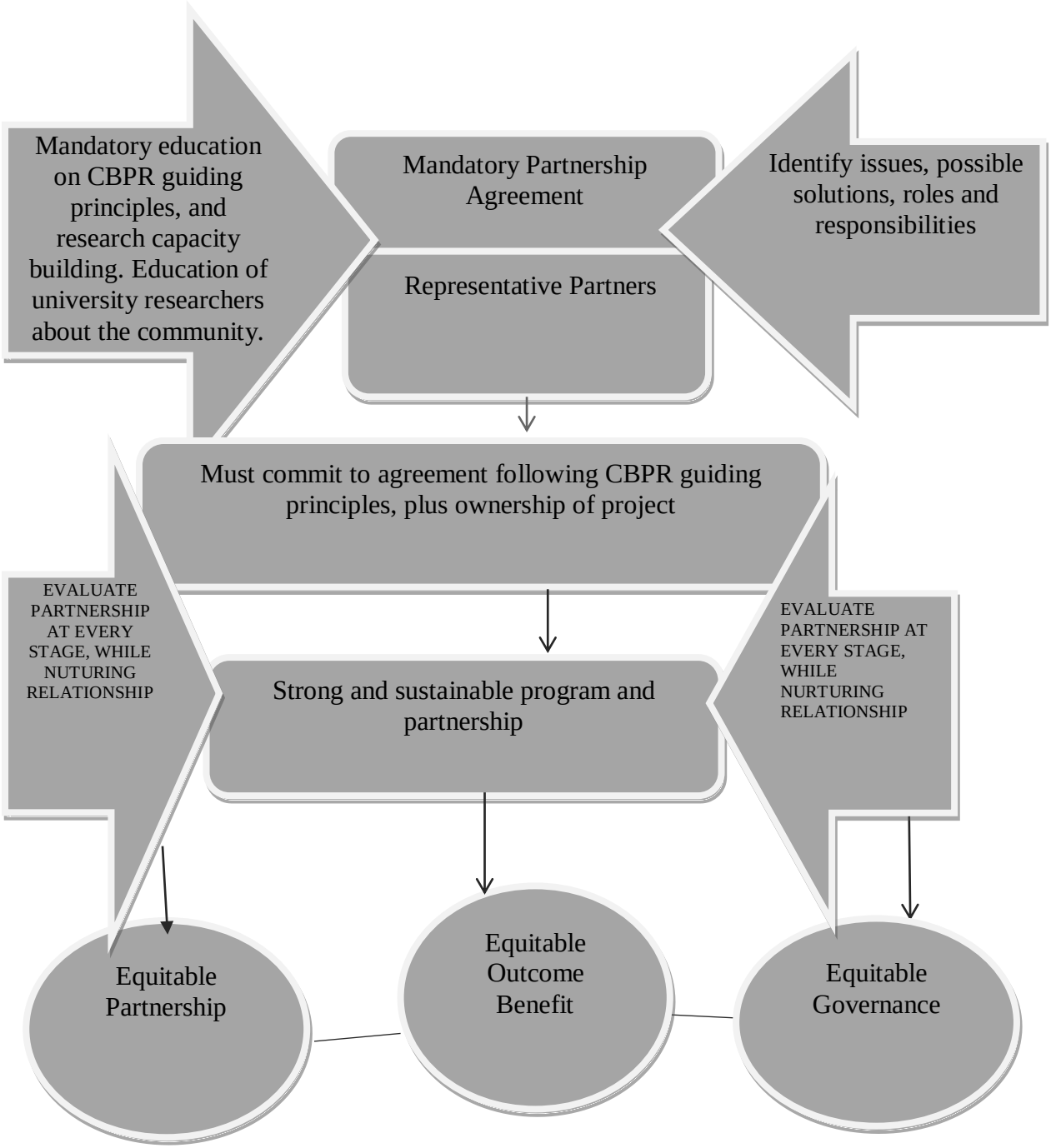

*Figure 5***.** Proposed CBPR partnership conceptual framework for sustainable parternship and equitable outcome benefit: Must Agree First Then Must Commit (MAFTMC).

The researcher's recommendations for authentic and equitable CBPR partnerships are highlighted in the MAFTMC proposed framework earlier in the chapter. The researcher also noticed the absence of a CBPR partnership evaluation in her study, and from the literature, there was not enough CBPR partnership evaluation, and established universal standard framework for evaluating Community Based Participatory Research. A future study on adopting a unique and workable CBPR partnership authenticity evaluation tool would enhance authenticity in CBPR partnerships. A mild tweak on the Belmont Report IRB requirement tailored particularly for CBPR would enhance authentic CBPR partnerships following the guiding principles, as also recommended by Shore et al (2015).

Other recommendations for successful CBPR partnerships made in this study come from the study participants themselves as seen in figure 6 below:

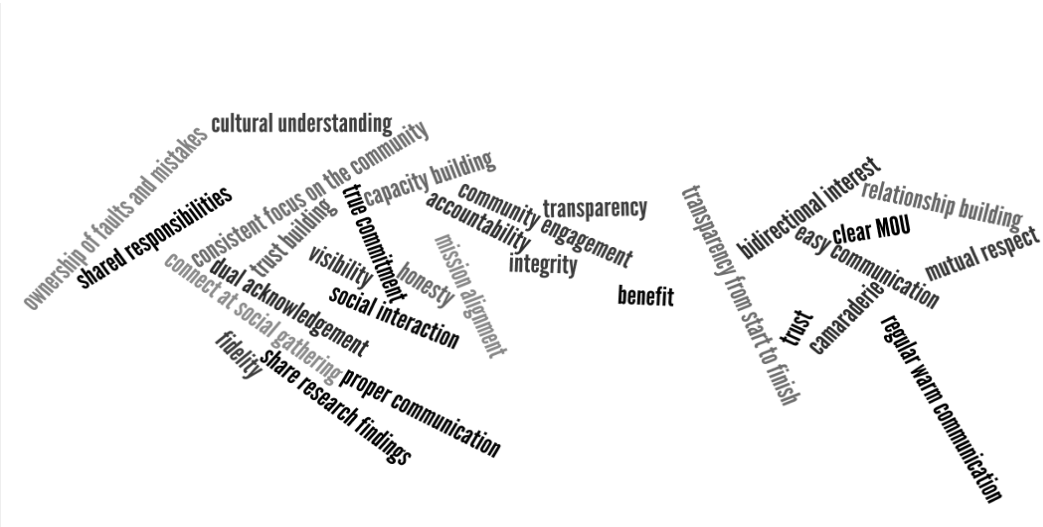

Figure 6. Success factor recommendations from community and academic partners.

Participants in this study provided some best practice recommendations to enhance and encourage long-term partnerships and program sustainability when funding ends. Such

recommendations included transparency from start to finish, bidirectional interests considered, equal access to funding money, consistent focus on the community throughout the partnership, cultural understanding, true commitment to partnership goals from start to finish, ownership of faults and mistakes, early definition of roles and responsibilities for each partner, and partnership fidelity.

This researcher drew from all the named words one overarching theme which is a thirst for community and university relationships nurturing, and some adjusted ethical requirements for CBPR partnership before, during, and after such collaborations as a factor to successful CBPR partnerships which may contribute to sustainability in partnership and programs. With true commitment to project goals, cultural and value understanding through early trainings, transparency and consideration of each partner's major priorities, due diligence and mutual respect, there could be a chance for positive long-term partnership outcomes and a sense of belonging to and ownership of a process that could affect positive change for the community.

Results in this study demonstrated a need for CBPR specific IRB requirements with a focus on CBPR guiding principles. This issue was raised mostly by academic participants who expressed that the IRBs were full of requirements from the Belmont Reports tailored specifically to traditional biomedical research. Most academic participants indicated that the lengthy and demanding research and textbook dynamics are unrealistic to real life procedures for CBPR and do not favor smooth partnership progress.

Using the above recommendations from participants in this study and drawing from some of the themes resulting from this study and literature, this research combined other factors that may play a role in enhancing effective and sustainable CBPR partnerships and programs. The idea of incorporating the evaluation of CBPR partnerships for authenticity into funding requirements is of utmost importance to ensure bidirectional benefits, sustainability, and colearning for all parties involved.

Limitations of Findings

Some community participants were not very knowledgeable about the depth of CBPR compared to academic participants and so certain questions where vaguely answered until the researcher probed to make sure they explored the depth of the questions. Although prior to interviews this researcher made sure all participants in this study had experienced CBPR or were involved in a CBPR partnership, it would have been better to fully be aware of their levels of CBPR knowledge for community participants. This researcher, however, made sure the interview questions were self-explanatory and easily understandable by all participants. Also, there also was some hesitation to answer certain questions by both community and especially academic participants who were very concerned about being identified especially by their respective academic institutions through their responses; to counter this concern, the researcher reminded participants that their identities and agency information would de-identified.

This is just one qualitative study, and results are not generalizable, although they may suggest commonalities with other projects or communities. Qualitative in-depth

interviews were administered to gather data on the level of authenticity in practicing CPBR guidelines and degrees of participation in the CBPR approach to research. However, the findings in this study do not provide the type of precise results obtained in quantitative studies on CBPR. Findings are not measurable but provide reasonable in-depth perceptions and opinions of participants in relation to processes, challenges, and recommendations for best CBPR practice.

A research gap in literature exists on the effectiveness of CBPR partnerships with university researchers initiated by community members. Since majority of community participants did not express full satisfaction in their partnership benefits, curiosity is raised to find out whether it would have been a different outcome if community partners initiated CBPR partnerships and whether it would promote a better sense of project or research ownership and commitment to the partnerships. Moreover, longitudinal studies of communities engaged in CBPR, to trace sustainability in relation to the research and interventions with examination of approaches to evaluation.

It is also important that CBPR project funding agencies and academic institutions recognize that productive CBPR partnerships take longer to yield fruit. Academic institutions should ease their faculty promotion requirements as it may lead to too much pressure on university researchers to quickly publish research, without taking time to truly nurture their relationships with their partnering community.

Implications for Social Change

CBPR academic and community partners in this study expressed a need to enhance the CBPR practice to ensure equitable and sustainable benefits. They expressed

challenges, barriers, and levels of involvement, and suggested recommendations for successful CBPR partnerships. The results of this study could benefit other researchers and community organizations, particularly those involved in or who plan to embark upon CBPR types of partnerships and initiatives.

The social change implication of this study is drawn from this researcher's designed and recommended CBPR framework for sustainable CBPR partnerships, MAFTMC, whereby a mandatory early agreement on role and responsibilities for both CBPR partners be established, education of community partners about the guiding principles of CBPR, training on research capacity in general, and academic training on community values, needs and culture prior to a project beginning, and true commitment to agreed roles and responsibilities until the documented end of the project, with consideration for program/project continuity. Being knowledgeable and educated about the mentioned principles would give community partners bargaining power during their partnership initiation, and academics a better understanding of community culture and rules governing the communities where they work. It would provide a sense of project ownership and empowerment for both partners, particularly the community partners, which is likely to enhance commitment, mutual benefit and program/project sustainability.

The CACT has been largely highlighted throughout this study in relation to sustainable partnerships and programs as one of the major issues experienced by both community and academic partners after funding ends. The above-suggested framework for sustainable CBPR practice serves a social change recommendation based on the views

expressed by participants in this study as well as literature and this researcher's analytical thoughts. This also ties in with the CBPR guiding principles and Arnstein's (1969) ladder of citizenship participation, which advocate for long-term equitable partnerships and involvement in all aspects of the research and partnership with equitable benefit for both partners. With this added literature, policy changes could be made to adjust IRB requirements for CBPR projects and partnerships with emphasis on including community representatives on IRB boards for CBPR. Moreover, both parties would better understand their bargaining powers during CBPR, from the drawing board to partnership/project completion, and they would be more likely to sustain their partnership and possibly undertake additional programs/projects to promote better health outcomes in communities.

Conclusions

CBPR is gaining recognition and emphasis in research approaches among funding agencies to ensure greater focus on social change and justice. This research approach, if applied authentically, could be the "next big thing" in the field of public health and other related fields if funders truly intend to promote a bidirectional benefit to both researchers and the community or people affected. This study has reconfirmed some challenges and benefits already highlighted in literature. Most of the challenges noted by study participants related to the process and equitable involvement in the research aspects of CBPR partnerships, raising questions of CBPR authenticity in most of the partnerships. A review of responses by community participants also raised the issue of awareness of true CBPR principles. Most community participants interpreted CBPR success differently.

Some based success on outcomes, while others based success on the fact that they were compensated and treated with respect. However, true CBPR is when all parties are involved in every aspect of the partnership, including the research phases, and benefit is equitable. There should be a true colearning opportunity in every aspect of the partnership through capacity building, as each partner brings specific expertise, as also recommended by current literature.

Challenges which included partnership and program sustainability after funding ends, partnership evaluation and total commitment to research and partnership agenda by community partners were noted. With these challenges, complete engagement of all partners in all aspects of the CBPR partnership from start to finish is crucial and could enhance commitment and sustainability. A process and outcome evaluation as a requirement by CBPR funders could also promote positive social change in communities.

It could be argued that when community members become aware of and are knowledgeable of authentic CBPR practice and its principles, they will realize their strengths and bargaining power in this research approach. An awareness of their bargaining power would mean proper negotiations from the onset of the partnership that would truly benefit each party. Bargaining that results in a Memorandum of Understanding also means that both parties will fully commit to smooth and relevant research priority, planning, implementation, and evaluation of project or program initiatives. Full commitment will lead to joint ownership of the initiatives, which may lead to interest in sustaining the partnership. Program sustainability through capacity-

building and ongoing evaluation should be the driving force of public health CBPR initiatives.

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Appendix A Interview Protocol

LOCATION_____

INTERVIEWER_____

INTERVIEWEE_____

AFFILIATED
ORGANIZATION_____

COMMUNITY MEMBER OR
RESEARCHER_____

DATE _____

TIME_____

***Interviewer*:**

- Thank you for accepting to be interviewed for this study. Your opinion is most important to me. I will not be giving my opinion or any instructions.
- Please feel comfortable with me.
- Your confidentiality will be highly respected in this whole process and after.

Before we begin, there are a few important points we need to pay attention to so that we can all enjoy this interview:

- Be free to speak your mind. Say what is true for you, whether negative or positive.
- Feel free to speak about your experiences.
- There are no right or wrong answers or opinions. I am looking for different points of view.

- As you can see, I have a lot to discuss with you. I may need to move quickly to different topics, but feel free to stop me if you have comments to add.
- We have about one hour for this interview, which is voluntary, meaning you can decide to stop when you feel like.
- Do you have any questions?

Appendix B Interview Questionnaire

	Community Member/ Partner	**Academic Researcher/Partner**
Please explain or briefly describe what you understand by CBPR.		
1. How long have you been in this CBPR partnership?		
2. Who Initiated partnership? Describe the initiation process.		
3. What was (is) the purpose of your partnership?		
4. Nature of their involvement (Arnstein's Ladder of Citizenship Participation)	**(a)** What are the characteristics of your community? **(b)** What community concerns or issues are (were) addressed in your partnership? **(c)** Which phases in the research partnership were you	**(a)** What are the characteristics of the community? **(b)** What community concerns or issues are (were) addressed in your partnership? **(c)** To what extent did (do)

	actively involved with?	community members feel they are fully part of the research? **(d)** Which phases in the partnership were your community partners actively involved with?
6. Origin of the research question: (Israel's CBPR Principles)	**(a)**Who was involved in identifying and in defining the researched problem? Please describe the process. **(b)** Is (was) the research supported by members of your community? If yes, please describe the method used by the researchers to get this approval. **(c)** If no, describe the research process without community support.	**(a)** Who was involved in identifying and defining the researched problem? Please describe the process. **(b)** Is (was) the research supported by members of the community you partner with? If yes, please describe the method you applied to get this approval. **(c)** If no, describe the research process without community support.
7. Process and methodological	**(a)** Does or did the process allow for	**(a)** Does or did the process

implications: (Israel's and CCPH's CBPR Principles)	learning about research methods and procedures? Briefly describe what you learned from your partnership.	allow for colearning? Briefly describe what you learned from the partnership.
8. Nature of the research outcomes and data management: (CBPR Principles and CCAT)	(a) Is there an explicit agreement between researchers and community participants with respect to ownership of the research data? If yes, please describe method. If no, who owns the research data in your partnership? (b) • Who designed research, • recruited participants, • collected data, • managed data • analyzed data, • wrote paper **(c)** How was research result disseminated, and who disseminated the results in your partnership?	**(a)** Is there an explicit agreement between researchers and community participants with respect to ownership of the research data? If yes, please describe method. If no, who owns the research data in your partnership? **(b)** • Who designed research, • recruited participants, • collected data, • managed data • analyzed data, • wrote paper **(c)** How was research result disseminated, and who disseminated the results in your partnership?

9. Partnership Sustainability and Long- term Commitment: (CACT and CCPH principles)	**(a)** What has been your experience with maintaining your partnership after project and funding ends? **(b)** Please describe how you maintained trust and communication in your partnership **(c)** Was community resources used taken into consideration during budget allocation for the project? Please list some of the resources included in the project budget **(d)** Based on your experience what are some recommendations for sustaining partnership during and after project and funding ends?	**(a)** What has been your experience with Maintaining your partnership after project and funding ends? **(b)** Please describe how you maintained trust and communicati on in your partnership **(c)** Was community resources used taken into consideration during budget allocation for the project? Please list some of the community resources included in the project budget **(d)** Based on your experience what are

		some recommendations for sustaining partnership during and after project and funding ends?
10. CBPR Success Factors: (Israel's CBPR Principles and CCPH principles)	**(a)** In your experience what are the factors that contribute to successful CBPR partnerships? **(b)** From your experience what are the barriers that interfere with your CBPR partnerships? **(c)** Based on your CBPR experience how did your collaboration empower your community?	**(a)** In your experience what are the factors that contribute to successful CBPR partnerships? **(b)** From your experience what are the barriers that interfere with your CBPR partnerships? **(c)** Based on your CBPR experience how did your Collaboration empower you and your partner?
11. Equitable Partnership Process, Procedures and Benefits of CBPR: (CBPR principles and Arnstein's Ladder of Citizenship Participation)	**(a)** Based on this experience can you say your collaboration in this project was a combined effort? Please elaborate. **(b)** How and when were roles and responsibilities for the project defined? **(c)** What was the fruit of your collaboration? Was there a research or abstract publication?	**(a)** Based on this experience can you say your collaboration in this project was a combined effort? Please elaborate. **(b)** How and when were roles and responsibilities for the project defined? What was the fruit of your collaboration? **(c)**What was the outcome of your

	If yes, Please describe authorship credits and roles. **(d)** Was there any form of compensation given to your organization before, during or after the project? Please describe the compensation if any.	partnership? Was there a research or abstract publication? If yes, Please describe authorship credits and roles. **(d)**Was there any form of compensation to the community before, during or after the project? Please describe the compensation if any.
12. Institutional Review Board ((IRB)Research Ethics)	**(a)**How do you and/or your organization protect yourself as participant in the research? **(b)** Did your partner discuss their IRB requirements with you/your organization? **(c)** Please explain the process, and how you feel it protected you/your organization.	**(a)** Does your institution have an IRB? **(b)** Please explain which ethical requirement is put in place by your institution to protect your research participants as individuals and as an organization? (**c**) Did your community partner obtain training about IRB

We have come to the conclusion of this interview. Thank you again for your time. I truly appreciate your willingness to be my interviewee. I will forward to you the transcript of this interview for any changes or additions and content would be used solely for the dissertation.

Appendix C Dr. Lawrence Green's Permission Email

From: "Green, Lawrence (Cancer Center)" <LGreen@cc.ucsf.edu>
Date: Mar 7, 2014 4:54 PM
Subject: RE: Request
To: "IVONNE ANGUH" <ivonne.anguh@waldenu.edu>
Cc:

You have my permission to use the instrument as needed in your work in Chicago. Let me know by e-mail at lwgreen@comcast.net if you need clarification of anything in the instrument. You'll find more details in the original report from Canada, and in the Appendix of the textbook on CBPR of Meredith Minkler and Nina Wallerstein, and on my website: www.lgreen.net. The website lists some of the other publications that have used the instrument.

Good luck with your dissertation.

Lawrence W. Green

Professor, Dept of Epidemiology & Biostatistics

School of Medicine

& Helen Diller Family Comprehensive Cancer Center

& Center for Tobacco Control Research & Education

& Clinical Translational Research Institute

University of California at San Francisco

Tel: 415-514-8115 or 415-205-6615

Prefer that you use LWGreen@comcast.net for e-mail

From: IVONNE ANGUH [mailto:ivonne.anguh@waldenu.edu]
Sent: Thursday, March 06, 2014 7:31 PM
To: Green, Lawrence (Cancer Center)
Cc: ianguh@csu.edu
Subject: Request

Dear Dr. Green,
I came across your contact online one of your articles.
I have had a keen interest in your research publications one of which I am deeply connected to.
I am a doctoral student in Public Health at Walden University finishing up my dissertation proposal on the topic of Community Based Participatory Research (CBPR).
I am curious about campus-community partnership for CBPR research in Chicago area and their degrees of participation and challenges. and I landed across your study on "Review Criteria for CBPR Applications", looking at levels of involvement, process and methodologies, origin of research question, research outcome.

I looked at your study instruments and crave to include them for my data collection with your permission.
I would be very grateful if granted the permission to use your study instrument on the above study in combination to mine. I promise to use it solely for the purpose of my dissertation and you will be given all the credits you deserve for your work. I would like to further discuss my study with you as needed.
Please permit me.
I look eagerly forward to your response.
Thank you.
Sincerely,

Ivonne Anguh, MPH, MBA