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Investigating Health Disparities through Community-Based Participatory Research: Lessons Learned from a Process Evaluation

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Abstract

This article describes one university's efforts to partner with a local agency (the “Coalition”) within a disadvantaged, predominantly African American neighborhood, to assist them with studying their community's health disparities and health care access. The final, mutually agreed-upon plan used a community-based participatory research approach, wherein university researchers prepared neighborhood volunteers and Coalition members to conduct face-to-face interviews with residents about their health and health care access. Subsequently, the Coalition surveyed 138 residents, and the agency now possesses extensive data about the nature and extent of health problems in their community. Lessons learned from these experiences are offered.

Keywords

Health disparities; community-based participatory research; university–community partnerships

Introduction

Persistent racial and ethnic disparities continue to exist and, in many cases, to worsen, for a wide variety of medical conditions and diseases that negatively affect the overall health and well-being of the United States' population. For example, African Americans face nearly twice the risk of experiencing a stroke compared to Whites and along with Hispanic Americans are more likely to die following a stroke than Whites (Centers for Disease Control and Prevention [CDC], 2011b). The prevalence of diabetes among persons of color has been reported to be approximately 2 to 3 times that of White Americans, and the increase of its occurrence among children of color is a growing concern (American Public Health Association, 2001). African American men experienced the highest incidence rates of colorectal cancer diagnosis compared with men in other racial/ethnic groups in 2007 and also face a greater burden of prostate cancer than White men (CDC, 2011a, 2011c). African American women are also more likely to experience colorectal cancer compared to other women. African Americans account for about 12% of the U.S. population, but they make up nearly one half (46%) of persons living with HIV in the United States. The rate of HIV infection for African American women is 15 times higher than the rate of infection for White women (CDC, 2010). Persons of color are more frequently exposed to environmental hazards that contribute to poor health outcomes, such as residing in inadequate living conditions and being exposed to airborne pollutants, and are significantly less likely to possess health insurance to address health concerns (CDC, 2011b).

Minority Participation in Research and Community-Based Participatory Research

The stark disparities in health outcomes between White and non-White Americans present pervasive and intractable challenges to the medical and social service professional communities. However, the discovery of interventions that may help to reduce or ameliorate these disparities has been hindered by the relatively low participation of persons of color in clinical studies. Researchers have questioned the extent to which past episodes of egregious ethical violations committed against vulnerable populations, such as the infamous Tuskegee syphilis experiment, continue to inform and skew African Americans' perceptions about contemporary medical research, its purpose, and value. Concerns persist about whether enduring skepticism and mistrust may partially or substantially explain the low participation rates of people of color in medical research (Corbie-Smith, Thomas, & St. George, 2002; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). Community-based participatory research (CBPR), which involves partnering with the community to identify and address problems regarded as important to its residents, has been shown to be successful in recruiting and retaining minority participants for inclusion in research (Baiardi, Brush, & Lapidus, 2010; Berge & Mendenhall, 2009; Israel et al., 2010; Jernigan, 2010; Mendenhall et al., 2010).

Critical factors in successful CBPR initiatives include a diligent effort to foster trust with the community partners, and meaningful and effective instruction in research methods necessary to carry out the project (Buys & Bursnall, 2007; Christopher, Watts, McCormick, & Young, 2008; Cross et al., 2011; Gehlert & Coleman, 2010; Mendenhall et al., 2010; Story, Hinton, & Wyatt, 2010; Wallerstein & Duran, 2010). Researchers have recognized the need to

train the community in research methods so that community-based organizations may truly participate on equal footing in all aspects of the research process, including identification of the research problem, survey design, Institutional Review Board (IRB) procedures, the informed consent process, and data collection and analysis (Hyatt et al., 2009).

University–Community Partnerships and CBPR Outcomes

CBPR partnerships of various kinds have resulted in a variety of improved outcomes for participants, including reduced blood pressure of community participants (Mendenhall et al., 2010), and successful acquisition of funds to address environmental concerns contributing to asthma diagnoses (Brugge, Rivera-Carrasco, Zotter, & Leung, 2010). Many successful CBPR projects often result from strong university–community (UC) partnerships (Jones, Pomeroy, & Sampson, 2009). University–community partnerships, with and without the use of CBPR, have achieved significant gains for a wide range of targeted populations, including the identification of novel approaches for addressing issues of grief and loss (Jones et al., 2009), increased exposure to science for educationally and/or economically disadvantaged students (Rumala, Hidary, Ewool, Emdin, & Scovell, 2011), implementation of an empowerment program targeting Latino/a youth (Rozas & Negroni, 2008), funding of intervention projects to address asthma (Brugge et al., 2010), creation of a culturally sensitive diabetes intervention (Mendenhall et al., 2010), and the development of outreach projects to address cancer disparities (Meade, Menard, Luque, Martinez-Tyson, & Gwede, 2009). The divergent array of initiatives undertaken by this sampling of UC partnerships demonstrates the advantageous versatility of this form of collaboration.

Developing University–Community Partnerships

The UC partnership literature discusses the process of developing partnerships, differing stakeholder perceptions of UC collaborations, and important components of and frequently occurring challenges to successful UC initiatives. Buys and Bursnall (2007) identified four stages in the development UC partnerships: (a) initiation, which answers the question, “Why should we partner?”; (b) clarification, addressing the question, “What is involved with the partnership?”; (c) implementation, assigning clearly defined project roles; and (d) completion, achieving the intended goals outlined for the partnership (2007). Strier (2011) observed that individuals involved in UC partnerships may have varied educational and professional expectations of the partnership, as well as differing instrumental expectations, that is, “What is in it for me?” and political expectations, that is, “How can this partnership help others or advance an agenda?” Problems in implementation and realization of project goals may result from unexplored differences in expected outcomes or benefits from such endeavors.

Others have noted that the time investment necessary to develop a working understanding of and trust with the community partner may involve committing two or more years to a project, and that this presents a complicating factor to meaningful collaboration (Gehlert & Coleman, 2010). However, when individuals indigenous to the community assume leadership positions as community advisory board members or community health advocates, for example, trusting relationships are more easily developed, and confidence in the value of the research to the community is supported and maintained (Baiardi et al., 2010; Story et al.,

2010). Researchers have also emphasized the great importance of having the right individuals from the partnership in leadership roles to provide project stewardship from within and across every involved entity (Amey & Brown, 2005).

Financial considerations have been identified as serious challenges to the success of UC partnerships. These types of relationships are often viewed as novel experiments by university administrators, and they may be wary to place fiscal and political support behind such initiatives (Lowe, 2008). Universities and community organizations should have strong operational infrastructure and seek financial backing and administrative support to implement these collaborative research efforts, as project delays due to lack of funding can become a source of frustration for community partners.

Current Project

Despite sharing a mutual interest in examining and eliminating health disparities, university researchers in a southern city and a local advocacy organization serving a disadvantaged and impoverished neighborhood (hereinafter referred to as “the Coalition”) within the city historically did not work together on these issues. A multidisciplinary research group of faculty at the university, the Health Disparities Research Group (HDRG) sought to develop more effective strategies to partner with interested community members and agencies to foster improvements in resident health and well-being, particularly among disadvantaged and at-risk populations. In late 2007, HDRG began to brainstorm with the Coalition to determine how they might work in partnership to benefit the neighborhood in question. Coalition advocates hoped that working with the research group would produce incontrovertible evidence to support the need for a free or low-cost clinic within the community, which could be presented to various funding sources.

What emerged from these strategic discussions involved a CBPR plan wherein Coalition advocates would be trained as “research apprentices” by HDRG volunteers to conduct face-to-face health surveys with residents, their own neighbors, and community members (see Jones et al., 2009; Mendenhall et al., 2010). This extensive undertaking involved several important steps: gaining the interest, engagement, and trust of organization advocates to work with the research group on the goal of completing the survey; training volunteers in basic research methods, including human subjects protections in research and interviewing; recruiting the community to work with university faculty to develop the survey instrument; and monitoring and facilitating follow-through on surveying neighborhood residents in adherence to the protocol (Berge & Mendenhall, 2009; Story et al., 2010). Ultimately, this process took 3 years to accomplish, but in so doing, 138 neighborhood residents were successfully interviewed by the “research apprentices,” resulting in a clear and revealing portrayal of medical conditions and health care concerns affecting the community. Additionally, useful lessons were learned about the challenges and potential power of UC partnerships that will help strengthen future collaborative efforts. What follows describes the collaborative process between HDRG and the Coalition, explicating the necessary steps to survey completion; identifies specific challenges and obstacles encountered during the endeavor; provides a descriptive, preliminary snapshot of the neighborhood survey results; and present results from separate focus groups held with HDRG and the Coalition that

documented their own oral histories of the partnership. Reflections from the study's principal investigator (PI) are also offered. Finally, implications for developing successful UC partnerships are discussed.

Description of Partners

The Coalition is a grassroots organization dedicated to improving the livelihood, health, and well-being of the residents of a predominantly African American, low-income neighborhood in a southern city. It is a non-profit, 501(c)(3) agency and a Community Housing Development Organization recognized by the U.S. Department of Housing and Urban Development. A key function through which the Coalition serves the neighborhood is by providing safe, affordable housing to low- and moderate-income persons. Its mission involves a focus on fostering development of a safer and healthier urban community and providing consistent community supports and services through educational and cultural programs.

The neighborhood in question straddles two densely populated zip codes. It is nestled deeply within what was formerly the thriving center of the midsize southern city in which it is located. The area has steadily declined since the 1960s, as shopping centers moved miles westward, the population decreased by half, and the government collapsed into bankruptcy (Mikell, 2005). Distinct demographic information is not available for the neighborhood, but it is thought to mimic that of the immediate area surrounding it. Of note, the area is almost entirely Black and a disproportionate percentage of the population (nearly one half of all individuals and families in one of its two zip codes) live below the poverty line. According to her records, the Coalition's founder estimates that today, the economically isolated area hosts approximately 1,400 households and 5,000 individuals. It is because of the decay of their neighborhood—including very low high school graduation and employment rates, the proliferation of abandoned and vacant houses, and increase in crime rates—that a group of women coalesced to form the Coalition in 1997, to effect change.

The university's Health Disparities Research Group (HDRG) was established in 2004 as a multidisciplinary group of faculty, students, and staff from five colleges at a public university within the same city. It is the research arm of the university's Center for Healthy Communities (CHC). It includes approximately 15 core and 20 affiliated members interested in addressing health disparities, and the use of CBPR as a vehicle to promote health equity is a key focus of current and future initiatives. The group and center are supported by funds from the National Center for Minority Health and Health Disparities (NCMHD).

The partnership formed naturally through mutual interests and a shared professional and social network. The Coalitions' charismatic founder spoke at a 2007 health disparities symposium sponsored by CHC, impressing CHC's research director with her passion and dedication to her community. Shortly after the event, the National Institutes of Health (NIH) Partners in Research Request for Applications was released, specifically requesting proposals involving community-academia partnerships. At this point, the research director contacted the Coalition to begin to identify ways the university and the Coalition could work together on a proposal submission.

Strategic Planning and Project Timeline

The nascent plan of collaboration was set around the use of CBPR, and through multiple planning meetings, the parties sought to apply for a NIH Partners in Research grant, submitted in January 2008. However, how to best invest resources and time from both organizations was a matter of extensive discussion, with the primary focus of the collaboration shifting and changing over time. Initially, several ideas were offered as possibilities: to conduct an environmental survey of the neighborhood to address dilapidated housing and related health/safety concerns, to identify and recruit neighborhood advocates who could take the founder's place as future Coalition and community leaders in the event of her retirement, and to develop training to enhance office and interaction skills for Coalition members to improve their ability to provide services.

Initial plan of collaboration, 2008 to 2009—By summer 2008, HDRG received notice that NIH did not fund the proposal, so plans moved forward to work on the goal of conducting office trainings for Coalition volunteers and staff, deemed to be the most feasible without federal funding. The CHC director (PI for a Center of Excellence on Minority Health Grant funded by NCMHD) pledged to support the implementation of such efforts under the umbrella of the Center of Excellence work. The CHC research director, tasked with executing this directive, found it difficult to put forward a concerted effort toward implementation amidst many competing priorities, essentially causing the project to lose momentum throughout 2008. In 2009, the availability of Recovery Act NIH funds reinvigorated interest in the initiative, and these were applied for in the spring of 2009, but this proposal was also unsuccessful. The project leaders believed it might be time to reevaluate the project and what its primary purpose should be.

Reimagining the project and reopening the dialogue: A focus on community health—It was mainly the lack of dedicated time by the CHC research director that slowed the process down and caused the loss in momentum; however, enthusiasm in the project's potential remained high between both partners. A powerful, unexpected benefit resulted from this: the project stall allowed for a more deliberative reflection on what the Coalition partners really wanted and needed from the university. This renewed the dialogue between the organizations with a more critical eye and purposeful approach in 2009. HDRG members realized that training office workers and recruiting community advocates to replace the Coalition's leader were likely not the best use of their academic and scientific resources. They questioned the appropriateness of university researchers with a shared primary interest in community health being involved with such endeavors, as these proposed activities were only at best tangentially related to the neighborhood's health.

Early on, Coalition members had expressed an interest in the poor health of neighborhood residents. The more specific and immediate goal of helping the neighborhood and the Coalition to identify community health needs clearly emerged, and the focus of the partnership became CBPR and health surveying of residents. This may not have occurred without the loss of momentum and opportunity to reflect on why the organizations were working together.

Preparing the research apprentices and project execution, 2009 to 2010—In late spring 2009, once the health survey objective was formulated, HDRG worked to obtain university IRB approval. During the summer of 2009 and while waiting for IRB approval for the survey, Coalition volunteers were trained in human subjects protections (IRB training) on the university campus and more meetings were held with Coalition volunteers at their offices to identify the scope of the survey. During the fall and winter of that year, the project once again suffered a stalled period due to the need to attain approval from NCMHD for project implementation under the Center of Excellence grant umbrella. This approval was received in December 2009.

Various meetings between HDRG faculty and the Coalition leader were held to organize the fielding of the project. At this point the CHC research director correctly identified that she should relinquish the principal investigator role on the project to another HDRG researcher who would make it his primary commitment.

In March 2010, meetings resumed to develop the neighborhood health survey instrument and construct a variable list, and to complete interview training. From May through June, Coalition volunteers and staff successfully surveyed 138 residents in the neighborhood. Finally, in the fall of 2010, the PI met again with neighborhood residents and presented initial results from the Coalition neighborhood survey about their health and access to healthcare. Overall, from inception to completion, it took 3 years to achieve the partnership's key goal of successfully conducting the neighborhood health survey and acquiring its results to use for advocacy efforts.

Resident Survey Results in Brief

The neighborhood health survey included a probability sample of 138 residents. Respondents were overwhelmingly female (95%). Almost one half (45.7%) were retired from the workforce or disabled and unable to work. One fourth of respondents (24.8%) were widowed. Forty percent were age 62 or older.

Key findings from the survey pertaining to respondents' health included the lack of adequate health insurance coverage, primary care access, and health care costs. The two top barriers to health care were cost (17.4%) and transportation to doctors (2.9%). Only 27.1% reported having a regular private primary doctor, and 33.3% indicated they had no doctor. More than 28% were without insurance. Almost one third of respondents had unpaid medical bills (29.7%), and almost 10% (9.7%) stated they had been refused medical care because of inability to pay. Several respondents also did not seek needed care because of outstanding medical bills (12.3%), and a substantial number did not get regular checkups (17.4%). Almost 11% reported taking less medication than prescribed to make it last longer, and an alarming 97.8% used emergency rooms for ordinary, nonemergent, health care. It should be noted that these findings are from a preliminary analysis of data and more reports from the survey's results are forthcoming.

Findings from the Process Evaluation

Oral History from Stakeholders Protocol

Focus groups were conducted with HDRG members and Coalition members separately, in an effort to learn from their experiences and to carefully document the history of this lengthy project. This aspect of the study was conceived of as establishing the oral history of the collaboration to acquire an understanding of the steps that led to a community partnership, the barriers faced, and the perceptions of those involved with the partnership. One evaluator led the discussion, while another served as a scribe and wrote notes and quotes on an easel board. Each participant was given a handout with the 12 primary questions so they could refer to them throughout the discussion. As easel pages were filled, they were removed from the easel stand and pasted on walls for display while the discussion continued. These focus groups lasted approximately one hour.

HDRG Members' Perspectives

The HDRG focus group was held in the fall of 2010, with four longstanding members who had the most involvement with the partnership over time. When asked how the partnership began, HDRG members recalled that the CHC office initiated the original contact with the Coalition. They remembered that the Coalition's founder was a presenter at a conference and made a very favorable impression on the CHC research director through her demonstrated commitment to the community. An opportunity to apply for funding to do CBPR arose in late 2007 (the original NIH submission from January 2008), so CHC contacted the Coalition. HDRG members remembered that the initial conversations centered around the Coalition's founder's fear that when she left, there would be no one left to carry on the Coalition's mission. The CHC research director had explained at that time that any collaboration would require a research focus due to the nature of the potential funding available. Given that need, a discussion then ensued about conducting an environmental survey of the community's residences. A meeting was held in October 2007, and in January 2008, letters of support were collected to formally initiate the collaboration.

Project participants and their roles—Key to establishing the relationship was the involvement of several dedicated HDRG members and the Coalition's founder. One community volunteer known to CHC who had already been working with the Coalition with some of their community improvement projects introduced the CHC director to the Coalition's founder and was the critical initial link between the two entities. Also, HDRG members recalled that two of the Coalition's staff were involved in strategic planning meetings from the beginning and saw the project through to its completion.

Several HDRG members reflected upon the engaging, dynamic and forceful personality of the Coalition's founder, viewing her as a critically important reason that the partnership was pursued and that the survey was eventually a successful initiative. She had been raised in the neighborhood served by the Coalition during the Jim Crow era. At the time, there was a strong Black middle class in the community. She left the neighborhood after finishing high school and moved to Atlanta, where she completed college. She returned to the

neighborhood to find it significantly deteriorated, and she made it her personal mission to improve the community in any way possible.

Initial project goals—When asked about the initial goals of the project, HDRG members recalled those previously mentioned that were eventually abandoned: the possibility of a neighborhood environmental survey, the identification of future community leaders to fill the founder's role, and office training for Coalition staff and volunteers. They described how these early ideas were abandoned over the life of the project in favor of the neighborhood health investigation.

Initial impressions of the collaboration—Some HDRG members reflected that initially, they thought the CBPR collaboration with the Coalition was a “wacko” idea. They admitted to holding assumptions about the neighborhood residents and volunteers prior to working with them that were eventually proven wrong. HDRG members' opinions of CBPR and the community in question changed over time. At first, university researchers questioned if it was feasible for community members to conduct research on their own neighborhood. Early in the partnership, one HDRG member recalled there were concerns about constructing the questionnaire, worrying that it would turn out to be a “blank canvas,” with little interest in or input offered from community volunteers. Instead, what they encountered was an invested and engaged group of Coalition staff and volunteers who were dedicated to the project, and the health survey questionnaire was developed through an iterative process between the partners. During this challenging phase of survey construction, HDRG members began to see that the Coalition volunteers were quite educated, and apprehensions about their abilities to fully participate as “research apprentices” were unfounded. Now, at least one HDRG member thinks that all CBPR should follow this model. All four HDRG focus group participants agreed that they would do this kind of study and use CBPR again. One stated, “I never thought this *wasn't* going to work. I've seen people rise to important levels before, despite a lack of education.”

Current perceptions of CBPR and lessons learned—All HDRG focus group participants reported that this was their first attempt to conduct CBPR and to develop this sort of partnership with the community. When asked what they learned about CBPR from this experience that they would apply to future community collaborations, they offered several insights. A central theme of many of these suggestions was that dedicated time from a leader on the academic side of the partnership is essential. They suggested that the progress of the project should be monitored closely throughout. A few HDRG members commented that the project lacked a formal structure and organization, and this may have impeded progress. One noted that future efforts should more carefully and rigorously enforce the research design, which would require intensive, hands-on and regular involvement by the university partners. The same HDRG member noted that the development of instrumentation was a “sloppy process” at times, and this too could be more efficiently completed in the future through stewardship by a dedicated faculty partner. One focus group participant stated, “This is why students hate group projects.” Another commented, “Partners need to realize that they each serve a distinct role, and the strength of the relationship is dependent on evolving trust.” A key implication arising from this

discussion is that the role of each of the partners should be made explicit very early in the planning process of any CBPR endeavor, and that this delineation of responsibilities should capitalize on all participants' strengths.

Further comments mainly addressed community culture, and how university partners approach historical and cultural differences between themselves and the community of interest. "These types of projects must be cognizant of cultural sensitivities of communities with which they wish to partner," one HDRG member stated. He noted that this was not the first attempt by university representatives to work in this particular neighborhood. He commented, "Prior experiences with university researchers and faculty affect community members' perceptions of a university presence." He further explained that these prior efforts were negatively viewed by residents as exploitative projects conducted by self-interested academics in need of research projects and publications. This commentary reflects the importance of treating the community, its history, and culture with respect and genuine interest in learning from its members as indigenous informants.

Coalition Members' Perspectives

In the spring of 2011, a focus group was held with four Coalition staff, including its founder, to offer them an opportunity to reflect on their experiences with the project. During the focus group, they too were asked about their memories of how the relationship between the Coalition and the university began and what the initial goals were, to identify if there were any important differences in how the two partners recalled the early phases of the collaboration. They also recalled that the university CHC director reached out to the Coalition's founder after hearing her speak about the dilapidated conditions of her neighborhood. However, they thought that the relationship began in 2008, not 2007 (records indicate that HDRG began communicating with the Coalition in late 2007). Coalition members also remembered the community volunteer who was working in the neighborhood, "taking pictures of all of the debris in the ditches," documenting the need for environmental clean-up, as key to connecting the two parties. They recalled the CHC health disparities symposium, where the Coalition's founder and the CHC research director were formally introduced.

Project participants and their roles—As to who was critical in establishing the partnership and successfully carrying out the project, Coalition members identified longstanding university partners, including the CHC director, and 12 Coalition staff and volunteers. As with the HDRG focus group, participants again championed the uniquely determined and resilient Coalition founder, stating with authority, "She gets the job done."

They then reflected on what strengths and characteristics these various individuals possessed that helped them to successfully complete this lengthy and complex endeavor. One stated, "It's 'doers' in the community. [They are] women of integrity." Another noted, "These are people of faith." One listed a number of traits: "Integrity, faithful, men and women of their word. They give of their time, their money. They are not procrastinators. They will give testimony about what has changed in their community since the Coalition's involvement." Another Coalition member commented,

They are caring about other people. The true spirit of [the neighborhood] is to show love toward one another. We are determined, and we are organized. We have women who never say no. I could easily come up with a list of thirty volunteers right now.

Initial project goals—Interestingly, Coalition focus group participants remembered the initial goals differently from the HDRG members' recollections. None of the participants made any mention of environmental surveys, leadership recruitment, or office training. Instead, they immediately began discussing the poor health of neighborhood residents and indicated that the purpose of establishing a relationship with the university was to potentially have a clinic built in the neighborhood, through whatever means were available. The Coalition recognized a need to conduct a survey, “to have proof that the need for a clinic in their neighborhood was there.” One noted, “Too many people here do not have health insurance and they live on a fixed income.” A Coalition member commented,

We've got a lot of sick people out here. Research with the university could justify the need for a clinic. We need a free clinic out here. We have people who charge others twenty dollars to take them to the doctor. It's ridiculous.

The hope was that this future clinic could be holistic in its mission and purpose, providing needed social services to people with mental illness and substance abuse problems. They also wanted a clinic capable of addressing teen pregnancy in the neighborhood. One Coalition member stated, “We figured if we got a clinic we could finally get a social worker out here.” Another similarly commented, “We need social programs and mental health treatment. That's the driving force for me, that, and premature babies. We've got kids in elementary school doing drugs and having sex.”

Initial impressions of the collaboration—In the beginning of the partnership with the university, Coalition members felt hopeful about its eventual success, but they were well aware it would take some time to accomplish. “I was sure it would work, but it wasn't going to happen overnight,” one stated. Once the plan solidified around a CBPR project with Coalition members and volunteers being trained as “research apprentices,” impressions of the prospective endeavor varied, from optimism, to skepticism and in one case, frustration and confusion. Reflecting on the prospect of becoming a “research apprentice,” one noted, “It was easier for us to go door-to-door because people know us, and we knew the health problems. We're just trying to get help out here for our people.” Another described her skeptical stance: “Research was intimidating at first; I was against research in the African American community because of people trying to use us.” A third focus group participant described her confusion early in the process, “Frustrating. I had a communication problem with [the university]. My understanding of what would happen and what actually happened were two different things. ‘Survey’ meant something different than I thought it did.”

Obstacles experienced by research apprentices—Coalition focus group participants were asked to further describe various obstacles and challenges encountered during their experiences as research apprentices. Key among these were communication barriers pertaining to explaining research design and its attendant technical terminology. A

variety of failures in execution occurred in the field due to these difficulties. One described this problem as “survey ‘jargon.’ The idea of sample selection was confusing.” Though a simple random sample of homes in the neighborhood was constructed, replacement became necessary due to the frequent occurrence of finding a vacated property on the list. “I was aggravated when I found out that forty vacated homes had to be replaced. We needed a better explanation of that,” one Coalition member stated. In relation to this, another commented, “I just thought we were done with those [vacated homes]. Boy, was I mad when I found out we had to go out and find more.” The project's principal investigator also had decided to replace those from the sample who refused to participate, and this added to the Coalition's workload.

Another issue that arose in the field was when the university IRB stamp expired, but being unfamiliar with IRB regulations and policies, the Coalition members and volunteers continued to use the forms. Once the principal investigator learned of this, the surveying was suspended until new forms could be generated and stamped. This greatly upset several Coalition members. One stated,

I didn't understand IRB, and because I didn't know about it, I couldn't educate my team. I had run off copies of consent forms, using my own money, and the IRB stamp expired. If I had known about the stamp expiring, I would have changed the schedule and I would have communicated it to my team.

Another commented, “If they want to be successful working in communities, they were taking for granted that we understood, but that was one of the things that had me frustrated.”

Two other complications that the Coalition members recalled were more closely linked to neighborhood volunteers' and Coalition members' inexperience with research and motivation to follow through to project completion. Several reported that their survey team members did not fully complete their portion of the forms, which contained identification codes and coder initials. Once again, this meant the process was stalled until that information could be relocated and coded on the survey forms correctly. Secondly, though the CBPR project was conceived as a true community project, with neighborhood volunteers working alongside the Coalition staff as “research apprentices,” ultimately the vast majority of the labor necessary was performed by Coalition staff and its founder. She noted, “My team hadn't done anything and I was aggravated. It went down to the wire, and everyone pitched in at the last minute.” The Coalition members admitted that this series of hurdles did cause some friction within the Coalition at the time.

Current perceptions of CBPR, the UC partnership, and recommendations—

Coalition members were asked to reflect on their feelings about the university and toward doing research in their community, and if their involvement in the project had changed their perceptions, whether positively or negatively. One stated that she knew that another member who was not present for the focus group believed the research to have been a waste of time, but in her view “every little bit helps.” In considering their feelings about their relationship with the university and if they had changed at all, one member commented:

In the 1960s I thought [the university] was a bunch of redneck Klansmen because they systematically neglected poor communities. That's the way I felt about all universities until I met [the CHC research director] at the health symposium, and met [the CHC director]. I saw the minority connections, and thought they could relate to our plight because both were minorities. After attending the symposium, I learned that the university cares.

They described the context of these skeptical perceptions, and at times precarious histories with universities. One stated vehemently, "I'm tired of you coming into our neighborhood using us a guinea pig to only benefit [the university]. I hate for people to use the neighborhood and not try to make it better." Another remembered interacting with a researcher from another university in the past, noting, "He used us for his betterment, for his books," which unfortunately soured the Coalition on partnering with universities. One Coalition member explained that they have tried to reach out to community colleges in the region to help them with their needs, specifically to find someone to train local contractors to test for lead in homes, but they refused to help.

The Coalition members indicated that this project did improve their perceptions of and relationship to the university. "What impressed me is that they came out to the community to meet. She [CHC research director] even came to our office in the 'hood.' She was making an effort." Due to her extensive involvement with this project and becoming known to many HDRG faculty, the Coalition's founder has become a popular speaker on the university campus across several departments, including social work, sociology, nursing, and medicine, helping to educate students about the neighborhood and advocating for needed reforms to help disadvantaged communities. She laughed,

[The university] is working me to death because I have all these departments I'm dealing with. I have to go to a lot of speaking engagements. I have to learn to say "no," but all of the attention does give us "bragging rights."

When asked how the university could improve how they work with communities in the future, based upon this experience, a central theme of how critical frequent and clear communication is to the smooth functioning of the partnership emerged. One noted, "Communication, training. The IRB process needs to be explained early on. You need to explain details early on, because if you don't there will be hostility." Another stated, "Break down into simple terms."

Others commented on aspects of partnership that focused on relationship dynamics: "The university has to look at the makeup of the community: economic, social, and cultural. If people don't interpret the environment correctly, there will be problems in communication with the community," one advised. To overcome skepticism, another suggested, "Explain how the partnership is a 'win-win' for the community and university." To foster the development of trust, a participant encouraged university partners to "be hands-on. You must go out and meet people in person."

The Coalition members also offered some precautions. They encouraged future partnerships to be inclusive of many different academic perspectives and knowledge areas, stating, "What the university is offering may not be what we need. The university needs to draw in

more than one department to address issues; there are a lot of different kinds of problems in the community.” Another stressed the importance of being culturally sensitive and respectful, advising, “Don't send a Black man to survey a Black male participant, just because of his race,” explaining that may raise suspicions of tokenism.

Coalition members were given the opportunity to offer any final observations and comments they wanted to share, and they were universally positive comments, identifying what worked about the partnership. They were strongly motivated to continue their work on the project through the dedicated efforts of the project's principal investigator and his ability to establish a trusting relationship with them. One noted, “The PI's ability to present, teach and train was a strength. I learned how to communicate.” Another reflected,

I learned how to get along with people. It's a status thing where ya'll think ya'll are better than us; with good communication, we were able to overcome that fear. I learned how to trust people [at the university]—they accepted that we knew what we were doing.

His efforts to maintain consistent communication with them in the field were also commended, with one commenting, “Consistent contact, reassuring us that we can do it, was good. I thought it was good they checked on us every week.”

Interview with the Project's Principal Investigator

A separate interview was conducted with the study's PI, the most deeply involved and heavily committed project participant from the university side of the partnership. He was the individual assigned primary responsibility for managing the project when the CHC research director relinquished the principal investigator role in early 2010. A sociologist and social scientist at the university, his perspective and observations frequently focused upon wide-ranging matters of social justice in disadvantaged urban communities and universities' obligations to those communities, despite the presence of institutional barriers that inhibit the development of these partnerships.

Relationship-building and embracing the idea of community—He believed that the most important aspect of his efforts that led to the successful completion of the neighborhood survey was the relationship he tried to form with the community. He explained:

The university doesn't have a great track record with that. I want to change that. Before, they would “dive-bomb” the community in an exploitative and self-serving way. It is most important that we stay there and not repeat that “dive-bomb” relationship. We need to express the sentiment in word and deed that “we're here and we're not going away.”

He noted that structural forces and organizational imperatives drive faculty activities and can inhibit their ability to embrace and support community initiatives, as these types of partnerships do not resemble traditional academic research endeavors. He recalled that he came close to ending involvement on another health-related university project because there are currently three places these low-income community residents primarily access health

care (low-cost clinics and the health department) out of 19 nonprofit, federally funded facilities in the region and poor residents “don't get what they need. No one is held accountable for this discrepancy. How do we collectively determine that everyone in [this city] has access to quality health care?” He observed that the Coalition “knows what's going on—they raise the university's awareness and make the university community consider issues ‘out of our comfort zone.’”

Lessons from the experience—Noting the execution difficulties with the survey process, he stated, “They were not professional researchers, and they have other things to do.” Also, he identified the eventual neighborhood resident attrition volunteers from the project as problematic; volunteers attended educational or planning meetings, but most surveying was completed by paid Coalition staff, and that was not how the project was envisioned by either partner.

Reflecting on problems encountered, he thought he should have spent more time supervising the process, going into the field with them, at least initially. Once it was set in motion, intensive supervision was necessary. He observed, “It is idealistic to think that we can train community volunteers to function at the level of social scientists. It reveals the hubris of the medical community in thinking that social science research lacks difficulty.”

He asserted that involving residents in research about their community is essential, but university collaborators need to be realistic about what community members can and want to do. He reasoned:

This is not their life; think about why they're doing this and what is a realistic outcome. They want to access services. [The Coalition] wanted and needed a community clinic. They needed to document evidence of that need. This is the outcome.

Other areas he would have improved upon included modifying the study protocol and time frame. He stated he would have sought to acquire a better sample less prone to selection bias by establishing other means to survey hard-to-recruit participants. He recognized that building trust takes more time than may be expected, and the time frame must reflect this need; the original study plan was optimistically designed to be completed in approximately one year.

He also emphasized that the availability of funding for these types of projects greatly affects what can be accomplished and how effectively it can be carried out. Survey respondents were not paid due to lack of funds, which likely would have improved the overall response rate. He stated that there should be a mechanism built into CBPR research to compensate community volunteers in some way: “We need to pay people for quality data.” Last, he made a plea for a realistic approach to CBPR that plays to the strengths of each partner. He thought that attempting to train community volunteers to do “hard core” survey methods missed the point of collaboration. “No training module could accomplish that. They can do some things we can't, through their indigenous knowledge and informal networks, and there are things we (university faculty) know how to do,” he observed. He also would have sought greater community involvement, particularly at the initial stage, to help with gaining access

to the community and in developing culturally appropriate and meaningful instrumentation. Further considering issues surrounding cultural differences, he noted that the high levels of training and education university faculty possess do not necessarily guarantee that they are culturally competent to work with and engage communities of color. He expressed a belief that this issue was pervasive enough to warrant specialized training before any new, extensive collaboration between the Coalition or other predominantly minority organizations and the university were initiated.

Discussion and Lessons Learned for Future Cbpr Initiatives

The lengthy and complex process involved in successfully carrying out a neighborhood health survey by university-trained “research apprentices” can be viewed as an inspiring and successful example of an attempt at authentic collaboration, and as a cautionary tale. However, learning the lessons from those missteps and miscalculations could prove invaluable. HDRG’s future strategy, as the research arm of the university’s CHC Center of Excellence, involves a continued exploration of these opportunities with community stakeholders and advocates. As such, it is imperative that this university research group learns from what worked best and what did not and takes that into consideration with any upcoming CBPR strategic plans. It is hoped that other researchers contemplating such approaches might draw from and consider their experiences while pondering their own courses of action.

During his interview, the project’s principal investigator mentioned three keys to the psychological dynamics of the partnership that worked to move the project forward: “1) relationship; 2) long-term commitment; 3) trust-building.” Although there is considerable overlap among those three components, they all emphasize something tangibly different from one another as well. As noted by university researchers and Coalition members, respect is important, as is the promise of mutual benefit, or at least an honest attempt at achieving it. Mutual respect and mutual benefit are likely integral components to any successful UC relationship trying to accomplish a complicated endeavor such as this. That can be distinguished from the length of the relationship (his second component), and it is possible that the trust formed was a function of the two, or was at least partially explained by the combination of the two and other unknown factors. He was a notably skilled communicator on the project, as described during the focus group with Coalition members, and this likely fueled the formation of his strong relationship to the Coalition and the neighborhood, and subsequently their trust of him. These key characteristics of project leaders were identified extensively within the CBPR and UC literature as well (Buys & Bursnall, 2007; Christopher et al., 2008; Cross et al., 2011; Gehlert & Coleman, 2010; Mendenhall et al., 2010).

It is equally important to point out the influence and leadership of the community organizer and advocate who heads the Coalition. An individual who leads an impoverished and disenfranchised community with an animated, energized voice, strong community backing, and cold, hard facts is a formidable force with whom to be reckoned. She has, in essence, taken it upon her shoulders to make structural, progressive changes to her neighborhood and she has succeeded in this goal many times over. She is an experienced community organizer

who has many friends and supporters. This type of person is a valuable commodity who must be sought out and recruited in some cases (Amey & Brown, 2005).

HDRG and Coalition members were satisfied with the results of the research apprenticeship project, but obviously there were unexpected complications and underestimated challenges that slowed down progress and killed momentum. It is clear that in this case, the focus of the project could have been more explicitly identified earlier in the planning process if the Coalition had explained in plain terms the neighborhood's most pressing concerns. However, engaging in that conversation required a level of trust that required time and personal investment (Lowe, 2008). The confidence to be transparent about one's expectations is dependent upon the formation of trust between the partners. If trust and transparency are a function of time invested into the endeavor, it is crucial to consider the time available to engage the community when planning CBPR projects.

The HDRG research team learned crucial lessons about the planning and execution of CBPR. The project depended on the competence and engagement of the project's principal investigator who devoted considerable time to the study. His capabilities and approach made it possible to develop an authentic relationship with the Coalition that has shown itself to be sustainable. He also made a long-term commitment to the neighborhood, and promised the Coalition that the study would be completed, regardless of any complications encountered.

It should be apparent that this relationship was mutually beneficial; the community could build their case for a clinic, and HDRG researchers could investigate issues that were hard to explore in the neighborhood. As Strier (2011) indicated, it is vitally important to consider the immediate and future effects of any CBPR study on a community, as this may not always be the case and may not result in a net gain. Over time, this project developed a very specific focus and mission, which made its implementation rather surgical when enacted. This eased the work of the "research apprentices," as it narrowed the content of their surveys.

Methodologically and pragmatically, the HDRG team learned that a project like this requires close supervision by a leader who is flexible and truly values the involvement and wisdom of community informants. They also recognized that a clear delineation of labor should be established early in the partnership that speaks to each party's strength, as noted by Buys and Bursnall (2007). These studies require funding and can only reach larger groups of people through the awarding of substantial grants. More researchers need to consider innovative ways to apply for grant funding with community partners in need of assistance (Hart, 2011).

The issue of cultural sensitivity and competence is paramount and pervasive in university partnerships with disadvantaged communities and cannot be dealt with superficially (Rozas & Negroni, 2008). Those who wish to participate in these studies as researchers must be willing and able to assess their own beliefs, prejudices, and stereotypes about people who are members of various vulnerable populations and consider their own ability to effectively contribute to the effort. They have to believe that they can become culturally competent with this particular community, so as to be able to comprehend their worldview, social code, and order, and therefore respond appropriately to the community's perceived needs.

In this specific case, trust grew from a genuine relationship that formed over the expanse of an extended project time frame. More faculty time and money invested would have made the work easier and more efficient, but ultimately it was successful because of the enthusiasm and perseverance of the Coalition and university project leaders. Based upon what was experienced here, it is recommended that future CBPR plans be more realistic about what people can do, establish a meaningful and appropriate division of labor that capitalizes upon strengths, sustain involvement in the community to foster genuine engagement and trust, compensate community volunteers and survey participants, and recognize and respond to the need for close supervision of research-related activities by employing a researcher with primary responsibilities to the project.

The project succeeded in its aim to complete a health survey of a disadvantaged neighborhood trying to justify the need for a clinic to serve the area. The Coalition was eventually successful in acquiring a clinic in January 2012. There was no apparent connection to the neighborhood health survey, because the gift was from a private donor and medical professional not involved with the survey. It is possible that news of the project and initiative spread by word-of-mouth throughout the medical community. But, even if unrelated to this ideal outcome, the activists of the Coalition are now armed with hard evidence they need to repeatedly draw attention to the condition of their neighborhood and to advocate for their fellow residents' well-being.

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