



Evaluation of the Community Child Health Research Network (CCHN) Community-Academic Partnership

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Evaluation of the Community Child Health Research Network (CCHN) Community-Academic Partnership

Abstract

Background: The Community Child Health Network (CCHN) is a research collaborative network of five communities in the U.S. formed to study maternal and child health disparities, via a community-based participatory research study design. CCHN studies how community, family, and individual level influences interact with biological processes to affect maternal stress, resilience, and allostatic load; ultimately, the study evaluates whether such factors result in health disparities in pregnancy outcomes and infant and early childhood mortality and morbidity. The purpose of this paper is to assess the community-based participatory research (CBPR) process that governs the CCHN and offer lessons from our experiences. **Methods:** This study employs a qualitative approach to evaluate the CBPR process among CCHN community and academic partners. Qualitative interviews (n=17) were completed by both community and academic CCHN partners. **Results:** Content analysis of qualitative data revealed six major themes (1) lack of necessary resources; (2) collaborative learning; (3) perceived benefits; (4) communication and education; (5) trust and expectations; and (6) sustainability. **Discussion:** The benefits and challenges of implementing productive, community-academic partnerships were present both at the local site-level and the network-level. Ultimately, the inclusion of community-based participatory research principles and methods enhanced the study development, implementation, analysis, and dissemination of findings. **Conclusion:** Lessons learned from a multi-site CBPR project, including strategies for managing learning and communication across different geographic sites, may be useful to other CBPR and multi-site community-based research endeavors.

Keywords

Community Based Participatory Research; Maternal Stress

Cover Page Footnote

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Randolph, Community Coordinator Rosalind German). The following individuals also made critical contributions to CCHN: the Data Coordination and Analysis Center at the Pennsylvania State University (PI Vernon M. Chinchilli, Project Coordinator Gail Snyder, Co-Is Rhonda Belue, Georgia Brown Faulkner*, Marianne Hillemeier, Erik Lehman, Ian Paul, Jim Schmidt, Michele L. Shaffer, Christy Stetter), Steering Committee Chairs Mark Phillippe and Elena Fuentes-Afflick*, and NIH Program Scientists (V. Jeffrey Evans, Tonse Raju) and Program Officers (Yvonne Bryan*, Michael Spittel, Linda Weglicki, Marian Willinger). We thank the hospitals and other facilities sponsoring participant recruitment and the local community advisory boards at each site. For a detailed overview of CCHN, please see the CCHN public website at <http://www.communitychildhealthnetwork.com>. *Indicates those who participated in the planning phase of the CCHN.

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(CCHN) Community-Academic Partnership**

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ABSTRACT

Background: The Community Child Health Network (CCHN) is a research collaborative network of five communities in the U.S. formed to study maternal and child health disparities, via a community-based participatory research study design. CCHN studies how community, family, and individual level influences interact with biological processes to affect maternal stress, resilience, and allostatic load; ultimately, the study evaluates whether such factors result in health disparities in pregnancy outcomes and infant and early childhood mortality and morbidity. The purpose of this paper is to assess the community-based participatory research (CBPR) process that governs the CCHN and offer lessons from our experiences. Methods: This study employs a qualitative approach to evaluate the CBPR process among CCHN community and academic partners. Qualitative interviews (n=17) were completed by both community and academic CCHN partners.

Results: Content analysis of qualitative data revealed six major themes (1) lack of necessary resources; (2) collaborative learning; (3) perceived benefits; (4) communication and education; (5) trust and expectations; and (6) sustainability. Discussion: The benefits and challenges of implementing productive, community-academic partnerships were present both at the local site-level and the network-level. Ultimately, the inclusion of community-based participatory research principles and methods enhanced the study development, implementation, analysis, and dissemination of findings.

Conclusion: Lessons learned from a multi-site CBPR project, including strategies for managing learning and communication across different geographic sites, may be useful to other CBPR and multi-site community-based research endeavors.

Keywords: CBPR, maternal stress, health disparities

INTRODUCTION

The Community and Child Health Network (CCHN) is a group of community organizations and universities working together to study how families, health care providers, and communities influence pregnancy outcomes and early child health and development in low-income and minority populations (Bloch, 2011; Cullen, Cummins, & Fuchs, 2012; Matthews & MacDorman, 2013). The CCHN consists of community partners and academic partners with social, behavioral, and biomedical research expertise who adapted community-based participatory principles to investigate disparities in perinatal outcomes. CCHN led a multi-site study on the effects of stress and resilience on parents' and children's health and well-being. CCHN's framework is designed to promote shared knowledge, trust, and idea generation that can lead to evidence-based interventions.

One of the challenges of conducting research in low-income and minority populations is the history of distrust of research (Gamble, 1997; Randall, 2006). A recent Institute of Medicine report notes that in the past decade, trust in the clinical research enterprise has declined, and "[n]early 73 percent of minority respondents reported it was 'very likely' or 'somewhat likely' they might be used as guinea pigs without their consent" in health care research (Institute of Medicine, 2011). Community-based participatory research (CBPR) may be one way researchers can engage communities, especially low-income and minority communities, around the importance of biomedical research to enhance the likelihood of executing research that is ethical, transparent, and relevant to local communities' priorities (McCloskey et al., 2011). Over the past two decades, CBPR has become an important approach for addressing health disparities in vulnerable communities (Wallerstein, 2006). In CBPR, the research question or issue to be addressed is developed through collaboration between the community and academic partners with the intention of addressing health disparities in the community (Minkler, Blackwell, Thompson, & Tamir, 2003). CBPR can also directly address health disparities through facilitating policy advocacy related to social and economic issues that are often at the root of community health disparities (Israel et al., 2010).

In community-based participatory research, affected community members serve as experts regarding the social and economic circumstances shaping risk and resilience for adverse health (Chung et al., 2010). Such research also includes partnerships with community members and offers numerous benefits, including increased relevance of the science to local community partners (Horowitz, Robinson, & Seifer, 2009; Israel et al., 2010); improved fit of study goals and study outcomes measures to the local communities (Cashman et al., 2008); improved minority recruitment efforts (Byrd et al., 2011; De Las Nueces, Hacker, DiGirolamo, & Hicks, 2012; Horowitz, Brenner, Lachapelle, Amara, & Arniella, 2009); and, most importantly, assurance that the proposed research and related interventions meet community priorities and needs (Jones L & Wells K, 2007; Merzel & D'Afflitti, 2003; Shalowitz et al., 2009; Wells & Jones, 2009).

Evidence suggests that CBPR has been successful in addressing maternal-child health issues in local community contexts (Jones et al., 2009; Pivik & Goelman, 2011; Vaughn, Wagner, & Jacquez, 2013). By leveraging knowledge from local communities and identifying community structures that will enhance the sustainability of potential interventions, CBPR initiatives have helped to determine appropriate locations for perinatal interventions (Caley,

Shiode, & Shelton, 2008), identify sustainable community-based ways to increase social support for pregnant women and identify sources of stress that may affect maternal health (Bermudez-Millan et al., 2011).

From the beginning, CCHN employed a Community-Based Participatory Research (CBPR) model in order to incorporate knowledge from selected communities with the latest scientific evidence about maternal and child health. CCHN has incorporated the principles of CBPR (Israel et al., 2006; Israel, Schulz, Parker, & Becker, 2001) as the cornerstone of the study, which recognizes community as a unit of identity and builds on community resources and strengths. CBPR principles include promoting active collaboration among partners and participation in every phase of research, fostering of co-learning, insuring that projects are community driven, disseminating results in a form desirable to the community, promoting the community as the unit of identity, and ensuring that research and interventions are culturally and contextually appropriate (O'Fallon & Dearry, 2002). For example, CCHN strives to achieve an equal and collaborative partnership in all aspects and stages of research, with a focus on power-sharing that openly addresses social inequalities and promotes co-learning, information exchange, and capacity building among all partners. Finally, CCHN provides results to all partners through widespread dissemination of results and honors a long-term commitment to the CBPR process and its sustainability (Carty et al., 2011; Schulz et al., 2005; N. Wallerstein & Duran, 2010).

The theoretical approach for CCHN-partnered research was based on a cumulative stress pathway model. Ongoing and cumulative stress has been shown to have a deleterious effect on health (McEwen & Seeman, 1999). Stress is a hypothesized pathway between race/ethnicity and socioeconomic status and disparities in health, including maternal child health outcomes (Dunkel Schetter, 2011). The CCHN theoretical model assumes that social status (racial/ethnic group, socioeconomic status) is associated with differential exposure to stressors, with some racial/ethnic groups and lower SES groups likely experiencing more stress compared to majority or higher SES counterparts (Dunkel Schetter, 2011). The CCHN multi-site partnership employed a CBPR approach to examine correlates of maternal stress and birth outcomes.

The purpose of this study is to evaluate the CCHN-CBPR process using a qualitative methodological approach. We examined the experiences of CCHN community and academic partners and the perceptions of network functioning among CCHN partners who were charged with studying the relationship between stress and racial disparities in maternal and child health within diverse communities across the country.

METHODS

CCHN Academic-Community Partner Structure

The CCHN sites that were selected and funded in 2003 include three urban (Baltimore, Los Angeles, and Washington, D.C.), one mixed urban-suburban (Lake County, IL), and one rural (Eastern North Carolina) area. These five sites were chosen based on a competitive grant review process in response to an NIH request for proposals (RFP) for a CBPR-based initiative to address disparities in maternal child health. As indicated by the RFP, members of the academic-community partnership were required to apply together. Academic-community partners selected via the NIH peer review process formed the CCHN. Once assembled, this multi-site academic community partnership developed a program of research surrounding the role of stress and birth outcomes among low-income White and Black and Latino/a families.

Each site has both an academic and a community co-principal investigator (Co-PI) and a project manager. The five academic institutions were paired with five community-based organizations with close ties and a long-standing history of serving the local community. Community partners included an urban local health department, a Healthy Start program, an urban organization that serves African American families, an urban community health clinic, and a community based-pregnancy support organization. Community co-PIs were representatives of these organizations with a history of direct contact with pregnant women and their families. Academic PIs all had experience in maternal-child health research. Community PIs included four women and one man of whom three were African American and two were white. Project managers were also community organization employees who resided in the local community.

All sites worked together with input from colleagues from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), the National Institute on Nursing Research (NINR), and the Data Coordinating and Analysis Center (DCAC) joined the project in 2006.

The CCHN study consists of two phases: the planning phase and the observational study data collection phase. The goal of the DCAC was to provide organizational, informational, logistical, and analytical support, as well as coordination, to the CCHN during the implementation of the Phase II study. The CCHN developed a working format, including a governing Steering Committee, subcommittees, weekly conference calls, and periodic in-person meetings, to develop study objectives and protocols. The CCHN 2.5-year planning period and 5-year data collection period involved numerous face-to-face, two-day meetings, as well as multiple weekly phone calls, to support the work of the network. The network also offers a website that is a central location for sharing, storing, and accessing network materials.

After a planning phase, the CCHN began its journey with a observational study (referred to as CCHN phase II) on the relationship between stress and maternal and child health outcomes. The observational study is intended to inform future educational, community, and clinical interventions to address stress and adverse pregnancy outcome risk reduction. Each site had a "consortium" contract between the community and academic partner that specified guidelines for the transfer of money from the grantee (either the community or academic organization) to the partner.

Through representation on the governing CCHN Steering Committee and other committees charged with developing the research plan and tools, CCHN community partners have been active leaders in all aspects of the CCHN study, including the design, implementation, analysis, and dissemination of findings.

Each CCHN site was funded up to \$400,000 each year during data collection for the longitudinal follow-up of study participants at that location. In total, 2,448 mothers and 1,383 fathers were enrolled in the study. Data collection at each site involved individual interviews, telephone interviews, and a collection of biomarkers at multiple time points. A diversity of sites was selected to facilitate the recruitment of women and children from a wide range of backgrounds.

Overview of the Analytic Framework for the Present Study

This study employed a qualitative methodological approach to evaluate the CBPR process among CCHN community and academic partners. Evaluation procedures were developed by the evaluator at the CCHN-DCAC in partnership with the CCHN Community Committee. The Community Committee is composed of at least one community partner ($N=5$) and one academic partner ($N=5$) from each site; however, the committee is open to all CCHN members. Weekly Community Committee phone calls helped to identify, review, modify, and approve all study instruments. Similarly, the community committee was responsible for data interpretation.

While the DCAC evaluation team conducted data analyses, the Community Committee discussed preliminary analyses of qualitative data and, during weekly calls, gave input on how to proceed with analyses. Community members provided critical insight and direction on interpretation of research findings, including how findings related to their organizations and communities.

Community members' understanding of context assisted researchers as they worked to understand the relationships identified by the analyses. Finally, a team from the Community Committee consisting of community and academic partners volunteered to participate in writing this manuscript.

A semi-structured interview guide was developed to assess the participant perceptions of the CCHN academic-community partnership. Current CBPR literature and previously tested CBPR questionnaires (Israel, Eng, Schulz, Parker, & Satcher, 2005), along with input from the CCHN Community Committee, informed interview development. The full Community Committee selected, vetted, and, in some cases, modified the final interview guide via email and weekly calls.

The IRB at the CCHN-DCAC reviewed and approved the evaluation. No incentives were provided to CCHN partners for completion of the interviews.

Qualitative Assessment

Semi-structured interviews were administered over six months in 2009-2010. Note that results of this evaluation reflect a phase of the research when sites were still in project implementation, including development and modification of instruments and preliminary data collection. Eligible participants included current community and academic Co-PIs and the project manager for each site. They were asked about their roles on the project; who they considered as members of their work team; the role that each team member plays on the project; how the team contributes to the network as a whole; perceived functioning of the work team; perceived communication and power structure; lessons learned; perceived benefits to the community and the scientific organizations; challenges and solution; perceived utility of CBPR; experiences with CBPR; and finally what else they would like to learn from the CCHN experience. The same CCHN DCAC evaluator (located externally to data collection sites) conducted all interviews.

While the community committee suggested interviewing all CCHN members, budgetary concerns limited the number of interviews; therefore, the committee agreed to interview only community and academic Co-PIs and project managers. Therefore, our methods and results focus on broader leadership and management issues as opposed to issues related to data collection and service delivery by other CCHN staff. Semi-structured interviews were administered via phone to CCHN community and academic Co-PIs at each site ($N=10$), the project director from each site ($N=5$), the academic co-investigator ($N=1$), and the community co-investigator ($N=1$),

totaling 17 participant interviews in all. Note that all CCHN co-PIs and project managers completed interviews, all of which were audio-recorded and transcribed verbatim.

Analysis

Through content analysis, emergent themes related to each interview question were identified. Descriptive, topic, and analytical were used. Descriptive Coding involved the storing of information about each participant's role in the CCHN (e.g. PI, Co-I, project manager). Topic Coding involved sorting the text into related groups and labeling them. Analytical Coding involved the creation of categories that expressed new ideas related to CCHN functioning, considering the interpretations in context (Creswell, 2003; Strauss & Corbin, 1990). All of these procedures helped to ensure that all themes identified were endorsed across multiple interviews. This process also provided inter-coder reliability and standardization among analysts. Codes not utilized were deleted from the analysts' code list. This procedure condensed the list to include only relevant codes.

After the content analysis, the Community Committee reviewed a summary of the initial results to ensure that codes and themes were not misrepresented and that important themes from the transcripts were not missed.

RESULTS

Six major themes were identified: 1) lack of necessary resources; 2) collaborative learning; 3) perceived benefits; 4) communication and education; 5) trust and expectations; and 6) sustainability. Below, we present supporting quotes from the participants for each of the six themes. Quotes from community members are denoted by "c" and those from academic members are denoted by "a."

Lack of resources: Participants felt that lack of budget was one of the biggest challenges of the CCHN. Although each site received \$400,000 per year, CCHN partners felt that this amount was insufficient to cover all personnel, equipment and data collection needs. While the issue of limited resources was brought up unanimously across CCHN partners, it is largely an issue of the CCHN and other large research studies in general and not specific to the CBPR process. However, budgetary issues affected the way different CCHN partners were able to conduct the necessary work and participate in this CBPR-driven study and is, therefore, discussed as a relevant theme to the CBPR process.

For example, community partners noted disadvantages due to the lack of research capital and inadequate funds to run the project.

"We truly did not have anything set up to do any kind of research." - c

"This project requires [research] structure that [our community site] didn't need before the academic partnership...[we] don't have large accounts with institutions to buy equipment like the academic institutions do and end up paying more for these things than academic institutions." - c

"Communities are using time and money they don't have" - c

"The study is underfunded—on a bad day I would say that it has been grossly underfunded. To collect this amount of data and this number of data points with quality people at the current funding level is not possible. " -c

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“We don’t leverage or have enough money for the community to do the community’s work”- c

“Some sites have more internal infrastructure and some places have more support for the project. Some sites have more support from their sponsoring universities than others. What sites feel is reasonable to do vary by site. Sites that have more institutional support think that more is possible. Just because one site can do it, doesn’t mean all sites can do something.”-c

Academic partners also felt under-budgeted to complete the current project.

“The budget and funding are perhaps the biggest challenges of all. We are underfunded; it’s horrendous; we all work partly out of dedication; I am way underpaid for the time that I put into CCHN... it makes me angry; I feel mistreated... funding is the biggest issue for CCHN”- a

Collaborative Learning: Across all interviews, both community and academic partners reported achievements and challenges related to collaborative learning. Collaborative learning occurred within sites, between community partners and academic partners, and across sites. For example, academic partners learned recruitment techniques from community members. Partners reported positive experiences with intra-site learning between academic and community partners:

“We have mutual understanding from both sides. We can all learn from each other (academic and community partners). Share our work in different settings. We meet the changing needs to be creative and innovative.”-c

“I have learned as a community member a tremendous amount from her (my academic co-PI). She has learned a lot from me. It would be nice to spend half a day together. There is nothing that we haven’t been able to overcome.”-c

Many instances of cross-site learning also occurred. For example,

“Whenever there is an issue with each site, each site is very helpful in providing [insight on] whatever they are doing [to include] us, so whenever we raise an issue, for example attrition, what we are doing to decrease attrition and increase the retention of our participants, so we discuss this in our call and each site speaks with other sites.”- a

Communication: The study involved large numbers of people from many different organizations, disciplinary perspectives, and data collection sites. Difference in perspectives sometimes led to communication challenges. For example:

“I think that [communication] is one of the largest challenges.. I think from the academic and the community side, we speak the same language; we just say it in a different dialect” - c

“The way academics, physicians in particular, talk can be hard to understand by community, and community’s needs can sometimes be frustrating for academics when

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they know that our funding is to do research, not to change the community through programs, which is a matter of funding.” -c

Some participants were also concerned with the overall communication strategies for delivering information within the network. Opportunities existed for developing new modalities for communication and building on the network infrastructure. For example:

“Meetings are overly scheduled and dominated with presentations and are incompatible with the open exchange to moving to the next level.” - a

“For the future, one way to improve communication may be by creating a record [how decisions were made] of some sort because there’s a community history of how decisions evolved and how we got to be where we’re at so we can learn from it collectively” - c

Other participants experienced effective and positive communication within their sites.

“We have open communication (community and academic partners), we can easily get a hold of one another to talk through issues; in fact, we just had a call late last night to work through the biomarker protocol.” -c

“We do not have any communication problems. We (community and academic partners) communicate openly.” -a

Perceived Benefits and Barriers to Conducting CBPR: Academic partners expressed that the CBPR approach contributed to the relevance of the research:

“The research wouldn’t be as rich, it wouldn’t be as meaningful, and they certainly would not be able to disseminate it to a broader audience without the input and help from the community.”- a

“For now the benefit is like a continuous learning process [in which] we are having to be a part of the CCHN project, and the long term is the outcome of the project and how we can use these outcomes to improve the quality of health-related issues to those participants as a sample from the [x] community.” - a

Community partners agreed that the CCHN partnership benefited both the community and academic research. For example, community partners felt that their community members gain valuable experience and credibility in research and the presence of researchers can benefit community-based organizations:

“This research is very rewarded at (partnering CBO). Part of what we are charged with ...is to look at health disparities. This was something totally new. Now, this is part of our approach to health disparities—It’s become an integral part of what we do. It’s opened up our eyes to other research.” -c

“I think it’s a tremendous benefit to the community to have a group of scientists that are working in an applied framework that are concerned about service delivery. I think

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[with]the more scientists we have that work in that framework, we can actually make a difference in people's lives.” -c

“... we have been able to do well at our site because we are able to work with a group of scientists who know how to interact with community and who are concerned about the delivery of results to service providers. We were working with scientists that already knew benefits of doing things certain ways. We didn't have to waste time going over community issues.” -c

“The benefit to the community is that it gives credibility for the capacity of a community agency to take the lead and for us in a CBPR type activity.” -c

Partners also felt that members of their community benefitted from CCHN activities, including learning about health issues and shaping research agendas. For example:

“I think our community members at our monthly meetings have benefited from all that education and sharing that we have done, and I have been told they have” - c

“They (community advisory board members) like the fact that they are learning a lot more about health issues; they feel [that] many people in the community feel like they would never have this understanding on prematurity and health disparities like they do if they weren't involved in CCHN.”-c

“Community stakeholders have a say in shaping what they [researchers] do.” –c

Trust and Expectations: Clear expectations for partners' roles was a key factor. In those sites in which clear expectations were set from the beginning, the activities centered around reaching those goals in a very positive manner. In other sites, however, the expectations were not clearly delineated from the beginning; furthermore, if differences in opinions surfaced, the activities were impeded. Additionally, in the beginning of the study development, a great deal of discussion centered on whether the study would be an intervention trial or an observational study. Many of the differing expectations and issues related to trust arose from the need to decide between conducting an intervention trial and an observational study. Ultimately, the decision called for an initial observational study and plans for a future intervention study. For example:

“The different perspectives [on intervention versus observational study] should have been acknowledged from the beginning; [it] took a long, painful time to forge a common ground.”-c

A few of the community partners felt that their expectations were not met due to differing network priorities and power imbalances within the network, although this was not the case at all sites. Also notable is that this concern was largely in the beginning of the study during the formation of processes, procedures, and committees. As a result, in some cases, a sense of mistrust arose between academic and community partners. For example:

“The community is at a disadvantage, operating within the world and rules of academia; a steep learning curve for community partners.”-c

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“And so how do you get all of those PIs to think about ‘with’ the word ‘with community?’ not ‘on’ the community, not ‘to’ the community?”-c

“I think that we have our meetings that we spend 90% time on the academic stuff and 10% time on community stuff.”-c

“ It would have helped to have an experienced facilitator who understood what to expect—what kind of conflicts to expect and that these conflicts are natural and then help to get the group to move forward.”-c

However, some community partners felt supported and rewarded by their academic partner.

“They (my academic partners) always make me look really good”-c

“It’s been a really good experience. I have had very minimal frustration with this project. I have felt enormously supported and respected by the academic team. We have an outstanding team”-c

“Our relationship is very easy—we are not dysfunctional. We may have different expectations and opinions but are not the source of animosity”-c

One solution to the trust issues between academic and community partners and to address differing expectations was the formation of the Community Committee in 2006 (year 3 of the project). A community partner leads the Community Committee, which is comprised of both academic and community partners, with the majority from the community. The Community Committee reports to the overall steering committee about site and CCHN-wide issues. The participants explain the role of the community committee:

“The [Community Committee] can deal with study design issues outside of being overwhelmed with academics in the comfort of the community committee...Since the issues are coming from a committee, [this] gives more clout than if one community member raised the issue.” -c

“The committee gives structure for interaction with community people to interact with academic people.” -c

Sustainability: Issues related to sustainability were similar among academic and community partners. All participants agreed that continued sustainability is dependent on the strength of the community-academic relationships.

“We don’t have the depth of relationships yet to sustain it... It would wither, so I am actually not comfortable with that. I don’t want any one person to be obligated. Not because I want to be able to leave, but I think that means we don’t have enough depth yet.” -a

“Sustainability is having a vision prior to the CCHN and keeping that vision in the forefront, meaning our vision is to share research with the community and share the community with researchers”-c

Some partners were already optimistic about sustaining their CCHN relationships:

“I think at this point in (site x) we have gotten, we have finally reached a point where we could stand on our own. You know we have built our alliances with our community and our academic partners where we have what we call program x, our partnership could actually do some type of intervention without CCHN and its umbrella”-c

“I hope the network doesn’t die out. I hope we can continue to look at the next question. It would be a shame not to get continual funding. We will continue to work as long as CCHN is there. It’s been 7 years now; I don’t see us stopping.”-a

DISCUSSION

The most challenging obstacle for the CCHN partnership was an insufficient budget. Community partners expressed particular concern that budgetary issues not only compromised their ability to conduct partnered research but hampered their ability to build the necessary infrastructure for a research project. Jones and colleagues (2007) suggest splitting the budget 50-50 in order to reflect equal partnership and power; however, if the budget is insufficient, even an equal split can cause frustration and exacerbate the power imbalance (Wells & Jones, 2009). Strong and colleagues (2009) recommend that funders provide bridge money between pilot and long-term research. In accordance with Williams and colleagues (2010), we further suggest that bridge funding is needed for initial research capacity building for community-based organizations before any specific research project begins. Hoeft and colleagues demonstrate that cost considerations for CBPR may differ from the typical grant budget and that items such as compensation for community partners, longer timeframes to account for competing interests among community partners’ time and items such as food for meetings may necessitate a larger budget with a different structure compared to more traditional grant mechanisms.

Managing trust and expectations across a contextually and geographically diverse set of partners with different disciplinary and organizational perspectives is critical to the success of a multi-site community academic partnership. Achieving trust and common expectations among all partners is often challenging; however, these achievements are critical to the success of CBPR initiatives (Allen, Culhane-Pera, Pergament, & Call, 2011; Hebert, Brandt, Armstead, Adams, & Steck, 2009). After discussing the results of this study on a CCHN Community Committee call, our community and academic partners suggested the following strategies :

1. Academic partners could shadow community workers and spend structured time on Community Based Organization activities to help them better understand community dynamics prior to launching a research project. In CBPR, there is typically a heavy focus on community members coming up to speed on research. While this focus is important, we also recognize the need for academic capacity building in the community.
2. Partners suggested the use of a neutral facilitator for CCHN full network meetings to improve trust and manage expectations in face-to-face situations. However, to manage day-to-day communication across multiple sites, the CCHN relied heavily on phone calls for communication. While the Community Committee served as the vehicle for promoting trust between academic and community partners, specific strategies for managing phone-based meetings would have been useful.

Future multi-site CBPR initiatives should consider open discussions about trust and how to manage expectations over the phone when non-verbal interactions are missing. The use of communication consultants with expertise in developing effective communication for non-face-to-face settings would be helpful at the beginning of the partnership.

CONCLUSION

Our results highlight the accomplishments and challenges of managing a cross-national CBPR initiative to improve maternal-child health. CCHN is a unique CBPR project in several regards: 1) the funder provided the impetus for coming together for purposes of collaboration; 2) five unique communities and community-academic partnerships came together as a CBPR network; and (3) the goal of the project was to study maternal, paternal, and child health disparities and collect descriptive and biomarker data as part of the CBPR process to lay the groundwork for a future CBPR intervention. As such, unique benefits and challenges emerged over the years of development and implementation. Our results show that, despite facing challenges early on in the network, CCHN has become a vehicle for collaborative learning about prenatal stress across diverse contexts, community-based recruitment, interviewing, and biomarker collection.

CBPR across multiple diverse sites calls for structural changes in the research process and in the relationships between researchers and communities studied, including accommodations for cross-site learning and approaches to encourage trust among sites and between community and academic partners. Our preliminary evaluation of the CCHN network provides insight on how CBPR can be used across multiple geographic sites to address a common issue: improving maternal and child health.

To date, the CCHN multi-site CBPR framework has facilitated the recruitment and collection of data on socio-demographic and biological markers (e.g., lipid profiles, cortisol) from mothers and fathers from racially/ethnically and geographically diverse backgrounds, including low-income Whites, Blacks and Latino/as. More than 60 percent of the mothers and nearly 50 percent of the fathers lived below 200% of the federal poverty level. Funders of such research and members of the review committees that evaluate proposals should consider the issues raised in the present study when they solicit, review, and manage CBPR research grants.

Our study has several limitations. Our evaluation only represents CCHN partners participating and their responses when the assessment instruments were administered. Note that the CBPR process is a dynamic process. The interviews featured in this study were conducted while partners were still in the trenches developing, modifying, and conducting the study. Perspectives would likely differ after all protocols were systematically implemented and the data were collected. Also note that only study PIs and project managers were interviewed. Our particular findings reflect only the beliefs of these partners. If "direct service" staff (e.g., staff enrolling people in the study and collecting data) had been included, some different themes would likely have emerged. Direct service staff may have provided more insight regarding day-to-day study logistics, such as how difficult it was to reach participants and to complete data collection. Lastly, since we promised anonymity to each partner during the interviews, information on how contextual and organizational aspects of each site may relate to qualitative themes is not presented.

Lessons learned through the CCHN CBPR process provide insight regarding effective ways to approach a CBPR project that involves multiple partners in different geographic regions. Negotiating the CBPR processes across multiple CCHN sites initially added to communication and budgetary challenges, yet ultimately, the efforts enriched collaborative learning through exposure to ideas, programming, and ameliorative strategies used by partners in multiple communities.

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*Indicates those who participated in the planning phase of the CCHN.

REFERENCES

- Allen, M. L., Culhane-Pera, K. A., Pergament, S., & Call, K. T. (2011). A capacity building program to promote CBPR partnerships between academic researchers and community members. *Clinical and Translational Science*, 4(6), 428–433.
- Bermudez-Millan, A., Damio, G., Cruz, J., D'Angelo, K., Segura-Perez, S., Hromi-Fiedler, A., & Perez-Escamilla, R. (2011). Stress and the social determinants of maternal health among puerto rican women: A CBPR approach. *Journal of Health Care for the Poor and Underserved*, 22(4), 1315–1330.
- Bloch, J. R. (2011). Using geographical information systems to explore disparities in preterm birth rates among foreign-born and U.S.-born black mothers. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 40(5), 544–554.
- Byrd, G., Edwards, C., Kelkar, V., Phillips, R., Byrd, J., Pim-Pong, D., ... Pericak-Vance, M. (2011). Recruiting intergenerational African American males for biomedical research studies: A major research challenge. *Journal of the National Medical Association*, 103(6), 480–487.
- Caley, L. M., Shiode, N., & Shelton, J. A. (2008). Community/campus partnership: Tailoring geographic information systems for perinatal health planning. *Progress in Community Health Partnerships: Research, Education, and Action*, 2(1), 23–29.
- Carty, D. C., Kruger, D. J., Turner, T. M., Campbell, B., DeLoney, E. H., & Lewis, E. Y. (2011). Racism, health status, and birth outcomes: Results of a participatory community-based intervention and health survey. *Journal of Urban Health*, 88(1), 84–97.
- Cashman, S. B., Adeky, S., Allen, A. J., Corburn, J., Israel, B. A., Montaña, J., ... Eng, E. (2008). The power and the promise: Working with communities to analyze data, interpret findings, and get to outcomes. *American Journal of Public Health*, 98(8), 1407–1417.
- Chung, B., Jones, L., Terry, C., Jones, A., Forge, N., & Norris, K. C. (2010). Story of stone soup: A recipe to improve health disparities. *Ethnicity & Disease*, 20(1 0 2), S2–9–14.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches*. Sage Publications.
- Cullen, M. R., Cummins, C., & Fuchs, V. R. (2012). Geographic and racial variation in premature mortality in the U.S.: Analyzing the disparities. *PLoS ONE*, 7(4), e32930.
- De Las Nueces, D., Hacker, K., DiGirolamo, A., & Hicks, L. S. (2012). A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health Services Research*, 47(3pt2), 1363–1386.
- Dunkel Schetter, C. (2011). Psychological science on pregnancy: Stress processes, biopsychosocial models, and emerging research issues. *Annual Review of Psychology*, 62(1), 531–558.
- Gamble, V. (1997). Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*, 87(11), 1773–1778.
- Hebert, J. R., Brandt, H. M., Armstead, C. A., Adams, S. A., & Steck, S. E. (2009). Interdisciplinary, translational, and community-based participatory research: Finding a common language to improve cancer research. *Cancer Epidemiology Biomarkers & Prevention*, 18(4), 1213–1217.
- Hoefl, T.J., Burke, W., Hopkins, S.E., Charles, W, Trinidad, S.B., James, R.D., Boyer, B.B.(2014) Building partnerships in community-based participatory research: budgetary

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- and other cost considerations. *Health Promot Practice*. 2014 Mar;15(2):263-70. doi: 10.1177/1524839913485962. Epub 2013 Apr 30.
- Horowitz, C. R., Brenner, B. L., Lachapelle, S., Amara, D. A., & Arniella, G. (2009). Effective recruitment of minority populations through community-led strategies. *American Journal of Preventive Medicine*, 37(6, Supplement 1), S195–S200.
- Horowitz, C. R., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream are researchers prepared? *Circulation*, 119(19), 2633–2642.
- Institute of Medicine. (2011). *Patients charting the course: Citizen engagement and the learning health system workshop summary*. (L. Olsen, R. S. Saunders, & J. M. McGinnis, Eds.). Washington (DC): National Academies Press (US). Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK91496/>
- Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., ... Burris, A. (2010). Community-Based Participatory Research: A Capacity-Building Approach for Policy Advocacy Aimed at Eliminating Health Disparities. *American Journal of Public Health*, 100(11), 2094–2102.
- Israel, B. A., Eng, E., Schulz, A. J., Parker, E. A., & Satcher, D. (2005). *Methods in community-based participatory research for health* (1 edition.). San Francisco, CA: Jossey-Bass.
- Israel, B. A., Krieger, J., Vlahov, D., Ciske, S., Foley, M., Fortin, P., ... Tang, G. (2006). Challenges and facilitating factors in sustaining community-based participatory research partnerships: Lessons learned from the Detroit, New York City and Seattle urban research centers. *Journal of Urban Health*, 83(6), 1022–1040.
- Israel, B., Schulz, A., Parker, E., & Becker, A. (2001). Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Education for Health (Abingdon, England)*, 14(2), 182–197.
- Jones L, & Wells K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*, 297(4), 407–410.
- Jones, L., Wright, K., Wright, A., Brown, N., Broussard, M., & Hogan, V. (2009). The healthy African American families' risk communications initiative: Using community partnered participatory research to address preterm birth at the local level. *Ethnicity & Disease*, 20(1 Suppl 2), S2–30–5.
- Matthews, T. J., & MacDorman, M. (2013). Infant mortality statistics from the 2010 period linked birth/infant death data set. *National Vital Statistics Reports*: From the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System, 62(8), 1–26.
- McCloskey, D., McDonald, M., Cook, J., Heurtin-Roberts, S., Updegrave, S., Sampson, D., Eder, M. (2011). Chapter 1 community engagement: Definitions and organizing concepts from the literature. In National Institute of Health, *Principles of community engagement* (2nd ed., pp. 1–42).
- McEwen, B. S., & Seeman, T. (1999). Protective and damaging effects of mediators of stress: Elaborating and testing the concepts of allostasis and allostatic load. *Annals of the New York Academy of Sciences*, 896(1), 30–47.
- Merzel, C., & D'Afflitti, J. (2003). Reconsidering community-based health promotion: Promise, performance, and potential. *American Journal of Public Health*, 93(4), 557–574.

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BeLue, et. al.

- Minkler, M., Blackwell, A. G., Thompson, M., & Tamir, H. (2003). Community-based participatory research: Implications for public health funding. *American Journal of Public Health, 93*(8), 1210–1213.
- O’Fallon, L. R., & Dearry, A. (2002). Community-based participatory research as a tool to advance environmental health sciences. *Environmental Health Perspectives, 110*(Suppl 2), 155–159.
- Pivik, J. R., & Goelman, H. (2011). Evaluation of a community-based participatory research consortium from the perspective of academics and community service providers focused on child health and well-being. *Health Education & Behavior, 38*(3), 271–281.
- Randall, V. (2006). *Dying while black*. Seven Principles Press.
- Schulz, A., Zenk, S., Kennan, S., Israel, B., Koch, M., & Stokes, C. (2005). CBPR approach to survey design and implementation: The healthy environments partnership survey. In B. A. Israel, E. Eng, A. J. Schulz, & E. A. Parker, *Methods in community-based participatory research for health* (1st ed., pp. 107–127). John Wiley & Sons.
- Shalowitz, M. U., Isacco, A., Barquin, N., Clark-Kauffman, E., Delger, P., Nelson, D., Wagenaar, K. A. (2009). Community-based participatory research: A review of the literature with strategies for community engagement. *Journal of Developmental & Behavioral Pediatrics, 30*(4), 350–361.
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques* (Second Edition edition.). Newbury Park, Calif.: SAGE Publications, Inc.
- Strong, L. L., Israel, B. A., Schulz, A. J., Reyes, A., Rowe, Z., Weir, S. S., & Poe, C. (2009). Piloting interventions within a community-based participatory research framework: Lessons learned from the healthy environments partnership. *Progress in Community Health Partnerships: Research, Education, and Action, 3*(4), 327–334.
- Vaughn, L. M., Wagner, E., & Jacquez, F. (2013). A review of community-based participatory research in child health. *MCN, The American Journal of Maternal/Child Nursing, 38*(1), 48–53.
- Wallerstein, N. B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*(3), 312–323.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health, 100*(S1), S40–S46.
- Wells, K., & Jones, L. (2009). Commentary: “Research” in community-partnered, participatory research. *JAMA: The Journal of the American Medical Association, 302*(3), 320–321.
- Williams, K. J., Cooks, J. M., May, M., Peranteau, J., Reifsnider, E., & Hargraves, M. A. (2010). Walk together children with no wasted steps: Community-academic partnering for equal power in NIH proposal development. *Progress in Community Health Partnerships: Research, Education, and Action, 4*(4), 263–277.