Investigating and Addressing Social Determinants of Health in a Community-Based Participatory Research Process

By

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INVESTIGATING AND ADDRESSING SOCIAL DETERMINANTS OF HEALTH IN A COMMUNITY-BASED PARTICIPATORY RESEARCH PROCESS

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Under the Supervision of Professor Stephanie Robert

At the University of Wisconsin-Madison

Community Based Participatory Research (CBPR) is well suited to addressing health disparities and the many socioeconomic and political factors that produce these disparities within and across communities. However, not all CBPR projects take steps to investigate the Social Determinants of Health (SDH) at various ecological levels; rather, they often focus primarily on changing individual health behaviors. This risks "victim blaming", as well as overlooking the many sources of health disparities at larger ecological levels.

To address this problem, this study identified ten CBPR partnerships that successfully investigated and addressed the SDH in studies concerning health disparities in the United States. Through interviews with academic and community partners in these projects, the following research questions were addressed: 1) What is the process by which SDH emerge, by whom and at what point in the research process? 2) What are the circumstances that promote investigating and addressing the SDH in CBPR projects? 3) What are the circumstances that inhibit investigating and addressing the SDH in CBPR projects? 4) How do perceptions about investigating and addressing the SDH within a CBPR project compare between academic and community partner dyads who work together on the same project?

Semi-structured telephone and Skype interviews were conducted with at least one academic and one community partner from each partnership. Qualitative content analysis and dyadic interview analysis were conducted to explore themes that emerged from the interviews.

Results suggest that factors including how long a partnership has worked together and, the political climate around topics addressed influence whether partners are able to investigate and address the SDH in CBPR studies. Dyadic analyses suggest that half of the partnerships showed no differences in perceptions regarding empowerment between partners working together on the same project. Four partnerships had minor discrepancies in perceptions of empowerment, and one partnership demonstrated substantial differences in perceptions with regard to empowerment.

Implications suggest that the length of time that partnerships have worked together may influence their capacity to investigate and address SDH. Future research is needed to determine how to foster meaningful and empowering research processes throughout the duration of CBPR projects.

Acknowledgements

I arrived at the University of Wisconsin-Madison in 2003, never dreaming this place would be home for the next several chapters of my life. I was entering undergraduate –learning more about who I was and who I wanted to be – and feeling optimistic about the future. Ten years have passed, and I am still hopeful and inspired. Through brutal winters and gentle springs, I have learned to love this place and the people I have met along the way. It is here that I have made dear friends and colleagues. It is here that I met my darling husband and beautiful son. And it is here that I was inspired to walk down the path of social justice throughout my lifetime.

Social work was not my major when I entered the UW. I was thinking psychology was more my thing. I soon realized that I would be required to take too many sciences classes to my liking and quickly changed programs. However, social work was not an automatic match. The field seemed too broad – the problems too big. I was unsure where I would find my niche. Ironically, what I have come to appreciate the most about this field is the interconnectedness of all systems, communities and individuals that cannot be narrowly defined into neat categories, pretty boxes. This complex universe is what inspires and stirs me to action in ways that clean lines and fixed measures never could.

So many people have made my journey at the UW memorable and warm. To my dissertation committee, infinite thanks and appreciation for the countless hours you put into nurturing me and helping me to refine my ideas. To my dissertation chair, Dr. Stephanie Robert, who enthusiastically rose to the challenge of advising me, even as I resisted conventionality at every turn. Steph, your experience, thoughtfulness, dedication and insane brilliance have made such a difference in how I understand and articulate my research. You challenge me to be mindful of my words and of my actions, and I thank you for never backing down. Thank you to

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Finally, to my lovely husband, Francisco, you are my balance point, my soul mate, my partner in crime. Thank you for always listening to me talk about social determinants and participatory methods way more than any engineer would care to hear. You help me to make sense of this crazy universe and keep me smiling through the chaos. You and Majua have given me a family here in Madison – my greatest source of balance and peace. I adore you.

Dedication

For all of the CBPR partners who made this work possible.

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INTRODUCTION

Health disparities disproportionately affect racial and ethnic minorities in the United States (U.S.) and are large and persistent over time (Syme, 2008; Williams & Mohammed, 2009). Racial and ethnic minorities often have high rates of chronic health conditions including cardiovascular disease, kidney disease, stroke, diabetes, hypertension, liver cirrhosis, and cancer (Kung, Hoyert, Xu, & Murphy, 2008; Syme, 2008; U.S. Department of Health & Human Services, 2009). In addition, several minority groups experience higher rates death for most conditions (Williams & Rucker, 2000).

These alarming differences in health may be fueled in part by disparate access to, or substandard, health care (U.S. Department of Health & Human Services, 2009). However, health disparities can also be explained by variation in several broad *social determinants of health* (SDH) such as academic attainment, poverty, environmental factors, stress, culture and social support (Dressler, 2004; Li & Robert, 2008; Mays, Yancey, Cochran, Weber, & Fielding, 2002; Niederdeppe, Bu, Borah, Kindig, & Robert, 2008; Robert & Booske, 2009; Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; Williams & Jackson, 2005; World Health Organization: Commission on Social Determinants of Health, 2008). Indeed, these SDH are associated with disparate health outcomes in ways that extend beyond individual level health behaviors and practices (Israel et al., 2010). Thus, solutions to this growing problem might address the variety of social factors that contributes to differences in health across groups.

One method that has been used to explore causes, consequences and remedies for health disparities is Community-Based Participatory Research (CBPR). The use of CBPR is well-documented in engaging underserved communities in research that reflects the concerns of local residents (Israel, Schulz, Parker, & Becker, 2001; Israel, Schulz, Parker, & Becker, 1998; Potvin,

Cargo, McComber, Delormier, & Macaulay, 2003; Rios, Montoya Soto, Graves, & Walker, 2008). CBPR is characterized by partnerships between community leaders and academic researchers and ideally fosters empowerment, equity, respect, and shared responsibility among all members of the research team. CBPR also builds on local strengths and resources in pursuit of community improvement and wellbeing (Israel, et al., 1998). Through active collaborations and shared expertise, researchers and community leaders work to achieve greater knowledge of a given phenomenon, which then benefits the health and well-being of involved communities (Israel, et al., 2001). CBPR projects benefit from these dynamic partnerships that often experience "success", defined as completing goals identified by the community (Israel, et al., 1998; Potvin, et al., 2003; Rios, et al., 2008).

CBPR is well situated to address the alarming social problems posed by disproportionately high rates of poor health in racially and ethnically diverse communities. This is due, in part, to the flexibility that CBPR provides in its approach to investigating and addressing health disparities. In line with CBPR core values and principles, community and academic partners seek to balance fulfilling research goals and taking action for social change to benefit the health and wellbeing of community members (Israel, et al., 2010; Israel, et al., 1998). Ideally, academic partners consider research questions that are important to community partners, and community partners encourage and support high quality research (Tajik & Minkler, 2007). Thus, the products of CBPR partnerships provide meaningful outcomes for all involved in the research process.

Still, rather than considering the larger social conditions that foster health disparities, as well as multilevel solutions needed to mitigate these complex social problems, many CBPR studies focus exclusively on changing public attitudes and opinions around specific topics (Beck,

Young, Ahmed, & Wolff, 2007) or changing individual health behaviors, which risks "victim blaming", as well as overlooking the root causes of health disparities (Israel, Checkoway, Schulz, & Zimmerman, 1994; Kannan, Sparks, Webster, Krishnakumar, & Lumeng, 2009).

Preliminary Investigation

There is, however, a small subset of CBPR studies that *do* address and investigate the SDH to varying degrees. Thus, questions emerge as to how partners have been able to attend to these social factors in light of competing issues, as well as what these studies may have in common. To help answer these questions, a preliminary investigation was conducted in which I reviewed CBPR studies that investigate and address the SDH to various degrees. In order to be included in this review, studies needed to satisfy the following five criteria (adapted from Minkler et al. (2008).

1. Study demonstrated excellence in the CBPR process, defined as living up to the core principles of CBPR practice (as described by Israel and colleagues (Israel, et al., 1998)). As cited, language used in the inclusion criteria is adapted from Minkler et al. (2008). In this report, Minkler defines the idea of "excellence in the CBPR process" by indicating that they are those studies that "live up to" the core CBPR principles. While concepts such as "excellence" and "live up to" may hold an implied meaning within the CBPR readership, additional research is needed to further define these concepts for the sake of clarity and evaluation purposes.
2. Study described and/or took steps to investigate and address the SDH in CBPR processes. This criteria refers to whether authors discuss the topic of SDH somewhere in their article and/or demonstrate steps to incorporate the SDH into their research questions, goals, framework, actions, outcomes etc.

3. Study demonstrated a clear commitment to improving the public's health and promoting health equity.
4. Study featured research in partnership with low-income, racial/ethnic communities in the U.S.
5. Study was featured in a publication from the last 5 years.

With these criteria in place, the search yielded 15 CBPR studies. However, it important to remember that community-based partnerships are constantly evolving and research studies are often ongoing. As such, efforts were made to locate the most recently published academic articles that provide current results of these collaborations. These recent articles form the basis of this literature review. However, at times it was necessary to refer back to previous articles published on the same studies to fill in missing information concerning such issues as reasons for partnership formation, project timelines and initial project goals. Looking to previous articles helps to ensure that noted gaps and limitation of current studies are based on fact rather than assumptions. The following section will discuss results of this preliminary investigation.

The significance of the preliminary work coupled with the current study is crucial in moving the field of CBPR toward a method that actively accounts for the SDH that influence every facet of our lives. According to Michael and colleagues (2008), our current approach to addressing health disparities:

> may in fact be contributing to the perpetuation of disparities in health outcomes by failing to address the social, economic, and political determinants of health. …[T]he key to eliminating health disparities lies not in attempting to prevent single diseases at the individual level, but rather in building capacity …in communities to identify and address the causes of ill health at the community level (p.281).

Michael and colleagues (2008) clearly demonstrate the potentially damaging effects of CBPR projects that do not consider how social factors influence health. Therefore, to advance CBPR beyond the potentially limited framework of individual-level change, an important next step is to examine the role of investigating the SDH, as this framework considers the multiple levels at which health disparities arise and operate. To advance the field of CBPR, I suggest that *all* studies that use this approach consider at least how and why SDH play a role in creating and maintaining health disparities.

This proposition is not meant to discredit a rich history of accomplishments experienced by CBPR practitioners; rather, it is a bold call to action. Despite years of research and investigation, racial and ethnic disparities in health persist, in part because we have consistently failed to examine and investigate the social, economic and political conditions that give rise to these disparities. Given our increasing understanding of how the SDH influence wellbeing (Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; World Health Organization: Commission on Social Determinants of Health, 2008), it is time that the field of CBPR responds by considering ways to integrate the SDH into all facets of the research process.

Preliminary Results

Once studies were located for the preliminary investigation, a thorough review and critique was conducted in order to identify themes common across articles. These main themes were: the length of time a CBPR partnership had been established prior to work on the current study; participation of a community advisory board (CAB) or other multi-sector advising committee; the socio-political climate in which the study took place; whether actions to investigate and address the SDH were taken at multiple social levels; whether outcomes that

resulted from investigating and addressing the SDH were developed at multiple social levels; sustainability of project processes and outcomes; use of media coverage of research; and empowerment across community and academic partners.

In addition to locating common themes, the preliminary investigation revealed an emergent taxonomy within the group of 15 studies. While all studies clearly discussed the SDH, many did not take actions to address these factors in the design of CBPR projects, nor did they attend to these factors as part of study outcomes. Only eight of the 15 studies investigated the SDH, as well as took actions to address these factors as part of study outcomes. Another group of four studies investigated the SDH of health and presented thorough plans to take actions to address these factors as part of future study outcomes. However, such action had not been taken at the time that the given study was published. Finally, three studies described the SDH but did not clearly take actions to actively address these factors as part of study outcomes.

Indeed this grouping scheme represents a hierarchical continuum from those studies that simply describe the SDH all the way to studies that take steps to address the SDH in many parts of the study design. While this grouping scheme presents a blatant value judgment (i.e. that those CBPR studies that investigate and address the SDH are "better" than those that only describe the SDH), in order to advance the field of CBPR, scholars can begin to consider how the SDH influence our approach to research and eventually move towards investigating and addressing SDH into all facets of the research process. After all, the core values and principles of CBPR recognize the importance of attending to multiple determinants of health and disease, as well as taking actions to improve the health and wellbeing of communities (Israel, et al., 1998). Therefore, this study exclusively analyzed those CBPR studies that investigate the SDH, as well as took steps to address the SDH in various parts of the study design.

To address this topic, four research questions were explored:

Q1. What is the process by which SDH emerge, by whom and at what point in the research process?

Q2. What are factors that promote investigating and addressing the SDH in CBPR projects?

Q3. What are the factors that inhibit investigating and addressing the SDH in CBPR projects?

Q4. How do perceptions about the process of investigating and addressing the SDH within a CBPR project compare between academic and community partner dyads who work together on the same project?

Theory

The SDH Framework and Empowerment Theory together provide the theoretical background of this study. This framework and theory help guide the conceptualization of how social factors influence health disparities – as well as the processes by which we address these factors – in ways that are equitable and meaningful to all research partners. The SDH Framework and Empowerment Theory have been used widely in previous CBPR studies of health disparities around such topics as youth violence (Griffith et al., 2008); Latino farmworker health and safety efforts (Postma, 2008); diabetes prevention for urban African Americans (Schulz et al., 2005); and perceived barriers to immunization among parents of Hmong origin (Baker, Dang, Ly, & Diaz, 2010). Together, this framework and theory help to illuminate the need to understand health disparities in ways that consider and value both individual and social factors.

Social Determinants of Health Framework

One underlying assumption of this study is that health disparities arise in society for a variety of reasons, including contributions from SDH. The World Health Organization (WHO) defines the SDH as:

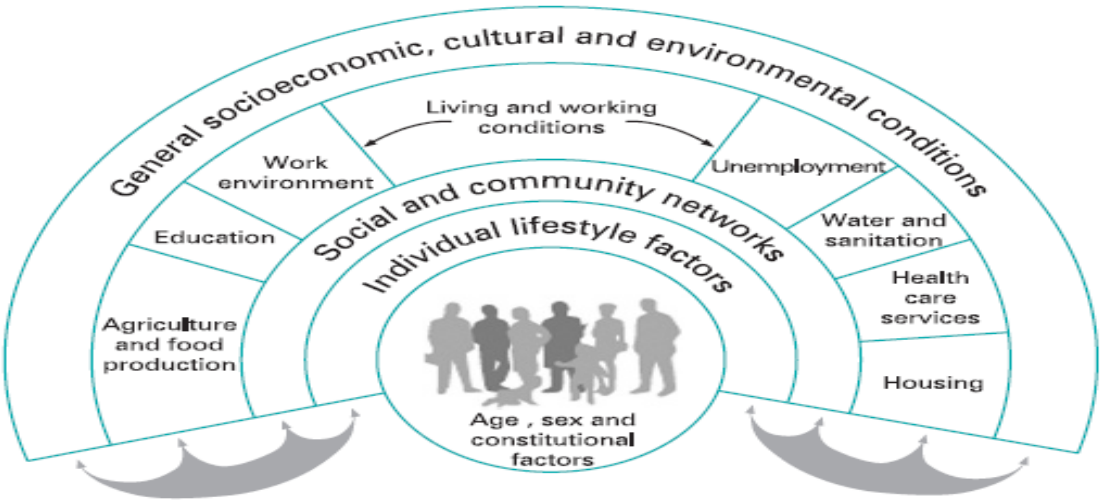
> the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices (2011).

This idea that social factors contribute to the creation of wellness and illness offers a distinct approach to addressing health disparities. The SDH Framework is not a theory per se, but rather a perspective that accounts for the variety of broad social factors that influence health across multiple levels (Schulz, et al., 2005). This framework posits that individuals are located within a circle of *social and community networks* that are further influenced by a wide variety of *broad socioeconomic factors*. These factors are then further embedded within a complex *socioeconomic, cultural and environmental context*. Factors, as well as proposed solutions, occur at multiples levels in which individuals are located within an ecological framework with bi-directional influences within and across social levels that contribute to health (or lack thereof) (Dahlgren & Whitehead, 1993; Krieger, 2008). See Figure 1.

Empowerment Theory

The ways in which communities work to address the SDH may help to ameliorate risk factors. A classic theory used to address health disparities within a CBPR process is Empowerment Theory. This theory takes a strength-based approach to working with communities that compels us to see community members as local experts capable of addressing the social problems that they confront in their daily lives (Perkins & Zimmerman, 1995).

Figure 1: Social Determinants of Health Framework (Dahlgren & Whitehead, 1993)



In addition, Empowerment Theory is rooted in the interconnections between power, powerlessness, and oppression (Gutierrez, DeLois, & GlenMaye, 1995). This theory posits that empowerment in the process by which individuals, organizations and communities gain control and influence over conditions in their lives (Fawcett, Paine-Andrews, Francisco, Schultz, & et al., 1995; Rappaport, 1987).

Empowerment Theory is unique in that helps to facilitate both an empowering research *process*, as well as empowering *outcomes* (Perkins & Zimmerman, 1995; Wallerstein, 2006). An empowering process refers to "intentional, informed participation, aimed at affecting change" (Becker, Israel, Schulz, Parker, & Klem, 2002, p. 700). Empowering outcomes refers to the power that is developed through this process and that can then be used to satisfy needs and to affect social change.

Like CBPR, Empowerment Theory is based on such values as collaboration, reciprocal relationships, a participatory process and power sharing (Fawcett, et al., 1995; Freire, 1970;

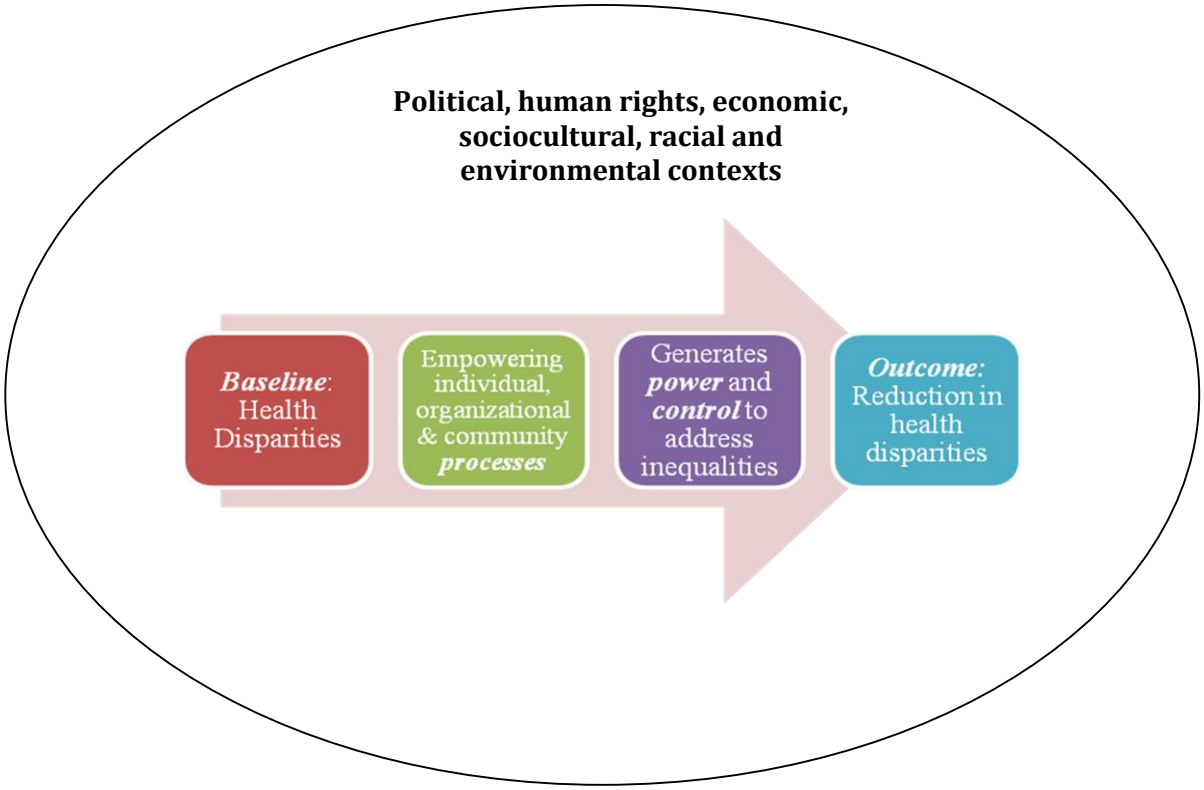
Maton & Salem, 1995; Rindner, 2004). The very nature of the relationships developed within an empowerment-based process help to foster confidence and agency, and may contribute to the richness and depth of the research process (Fawcett, et al., 1995; Freire, 1970; Rindner, 2004). In other words, the process of sharing power across academic and community partners (a relationship often unbalanced with respect to power) enhances research such that gains in empowerment are more likely to occur. As such, empowerment theory is useful in assessing power dynamics within partnerships, as well as how individuals respond to and internalize potential differences in control and influence.

However, it is important to note that the value of reciprocal relationships – in which community and academic partners hold equal power in the research process – may conflict with an investigator raising the issue of SDH. In other words, because Empowerment Theory values the ability of both sets of partners to mutually agree on questions that are important to research, how, when and by whom the topic of SDH is raised is important. There may be agreement between partners that SDHs are important to investigate in order to reduce health disparities, but it is crucial that all partners understand and agree to this way of addressing the problem.

Empowerment and health. When applying Empowerment Theory to studies of health disparities, research suggests that there is a positive relationship between empowerment and health. As such, individuals, organizations and communities that are more empowered generally experience better health (Becker, et al., 2002; Wallerstein & Bernstein, 1988). In addition, Empowerment Theory offers both direct and indirect benefits to health (i.e. reductions in a specific disparity, or the development of health protective relationships respectively) (Wallerstein, 2002). When working from an empowerment perspective, it is important that community members understand how their struggles are located within a larger sociopolitical

system without discouraging them from taking actions in spite of significant barriers (Tajik & Minkler, 2007). See Figure 2.

Figure 2: Empowerment and Health Theory Diagram, Adopted from Wallerstein (2006)



Research Design and Strategies

Study Design

This qualitative study uses semi-structured interviews to examine how CBPR partnerships investigate and address the SDH in studies of the disproportionate burden of poor health experienced by low-income racially and ethnically diverse communities in the U.S. Because this study is exploratory in nature, interviewing community and academic partners across a variety of geographic settings, topic interests, and investigator styles and

preferences helps to create a baseline understanding of how this phenomenon operates. In addition, understanding the process by which SDH are investigated and addressed within a CBPR process cannot be witnessed at discrete intervals, thus interviews provide a space for respondents to reflect on current aspects of the CBPR process, as well as to speak retrospectively.

However, there are inherent limitations that result from the use of exploratory methods, which may require future research that employs a variety of analytic methods be used to verify findings. Nevertheless, when examining topics for which little prior research has been conducted, as is the case in this study, an exploratory approach provides a necessary foundation for future study (Michael, Marion, & Dapiran, 2006). In addition, qualitative methods add flexibility, rich description of issues, and a holistic approach to this research (Hull, Taylor, & Kass, 2001).

Sampling strategy. A sample of ten CBPR partnerships (i.e. at least one academic partner and one community partner per project) was contacted by telephone and email to assess their interest in participating in the study. CBPR partnerships that investigate and address the SDH, which were identified in the preliminary investigation, provided an initial sample of partners to contact. Purposive, snowball sampling methods (Miles & Huberman, 1994) were employed in order to reach a sample of ten CBPR partnerships. Interviews lasted approximately one hour.

Procedures. The specific process by which participants were sampled and interviewed was as follows:

1. Academic partners were contacted first by using public contact information from published articles or university websites. When they agreed to participate, academic

partners were given the inclusion criteria outlined in the background and significance section in order to guide their selection of a project to reflect on during the interview for the study. At least one academic and one community partner from the same project agreed to participate in order for partners from that project to be eligible for this study. This was because a dyadic interviews analysis (see below) was used to consider the fourth research question, which compares and contrasts the perceptions of academic and community partners who worked on the *same* study. However, no more than two academic and two community partners were interviewed for each partnership, as only partners highly involved with investigating and addressing the SDH were of concern in the study.

2. Academic partners were asked to provide a wide range of dates in which they would be available to be interviewed. Because significant changes in CBPR projects can occur over a short period of time, interviews for the same project were conducted within the same month if the project was in progress. If the project was already complete, such deadlines were less important. In the case of projects in process, the first academic partner contacted was asked to provide several possible dates to be interviewed. When contacting other academic and community partners, interviews were scheduled around the dates offered by the first academic partner.

3. Academic partners were asked to refer me to any publications, community reports, grant applications or other background information about the project in order to orient me to the project before the interviews took place.

4. Academic partners were asked to identify other academic and community partners who worked with them on the study that they selected. Other academic partners were

contacted directly using public contact information available on published articles or university websites. However, to honor the confidentiality of community partners' contact information, academic partners were asked to contact community partners to inquire if they would be willing to participate in the study. Academic partners were emailed a copy of the contact information form (see Appendix A), which they were instructed to share with their community partners. If community partners agreed to participate, they filled out the study response form and returned it to me, or contacted me directly to learn more about the project and to schedule an interview.

5. If they agreed to participate, community partners were asked if there were other community partners who were involved in the CBPR partnership whom they believed should also be interviewed for this study. When there were other community partners whom they felt should be contacted, the current community partners were sent a copy of the contact information form that they were instructed to share with additional community partners. Other community partners who agree to participate filled out the study response form and sent it to me, or they contacted me directly.

6. All interviews were scheduled over the phone and participants chose whether the interview was conducted individually or with another academic or community partner from the study. However, when participants elected to be interviewed with another person, only pairs of academic partners and pairs of community partners were interviewed together.

7. All partners who agreed to participate were sent a list of interview questions in order to prepare for the interview. Preparation for the interview was needed, as questions asked respondents to reflect on, and describe in detail, early stages of research projects

that may not have been clearly documented. Therefore, taking time to talk with other members of the research team was necessary in order to respond fully and accurately to interview questions. In addition, participants were sent two copies of the consent form (one for their personal records and one to return) along with a prepaid envelop to return a signed copy of the consent form.

8. Data were collected by way of semi-structured interviews over the telephone or Skype depending on the preference of the respondent(s).

9. A digital recorder with a microphone attached to the telephone receiver or computer speakers was used to capture data accurately and was approved by the participants.

10. Participants were asked a series of interview questions (see Appendix B) concerning their work on a CBPR project that investigates and addresses SDH. Two interview guides – one for academic respondents and one for community respondents – were created. This was done to tailor how questions are asked so that they make sense to two different audiences (i.e. academic and community).

11. Participants were informed that a $400 donation to the American Cancer Society was made in honor of all partners' time and dedication to this study.

Analysis plan. First, interview recordings were professionally transcribed verbatim and checked for accuracy. Next, to answer the first three research questions, a qualitative content analysis – a methodical, empirical technique – was used to analyze text within and across interview data (Mayring, 2000). Questions 1, 2, 4, 5, 7 and 8 from the interview guide provided data to be analyzed in this content analysis.

The qualitative content analysis consisted of the following steps: First, hard copies of all interview transcriptions were reviewed by me and a second coder using an unrestricted *open-*

coding process, which is used to inquire broadly and to identify emergent themes from the raw text (Berg, 2004). At the end of this process, both coders convened to compare codes in order to increase the reliability and validity of findings, and a preliminary list of themes was compiled. Next, interview transcripts and the preliminary list of themes were imported into NVivo9 qualitative data analysis software (QRS International, 2010) in order to assist in recoding. Recoding helps to ensure that themes were not overlooked in the open-coding process and also allows for the further revision and development of themes. The purpose of the qualitative content analysis was to gain a baseline understanding how academic and community partners conceptualize the process of investigating and addressing the SDH within a CBPR process.

In order to address the fourth research question, a dyadic interview analysis was conducted. Questions 2, 3, 6, 7 and 8 from the interview guide provided data to be analyzed in this dyadic interview analysis. In this method, "dyadic" refers to the dynamics and relationships that transpires between individual members of a dyad, or pair, as well as their shared or discordant meanings of a particular phenomenon (Eisikovits & Koren, 2010). The purpose for using this method was because the fourth research question concerns the dynamics between academic and community partners, considering the *partnership* as the unit of analysis.

The process of conducting a dyadic interview analysis begins in the same manner as a content analysis outlined above, seeking to identity consistent themes across text. For the purpose of this study, dyads were interpreted broadly to mean the two sets of partners (academic and community) that form each individual partnership. Thus, all partners interviewed for the same project were included in the dyadic interview analysis for that discrete case, and themes were based on the overlap and differences between academic and community partners in the project.

Dyadic interviews analysis specifically examines the *intra-partnership dynamics,* in which each partnership is considered a discrete case. This is done by "assessing contrasts and overlaps between the individual versions" (Eisikovits & Koren, 2010) (i.e. between what is reported by the academic partner and what is reported by the community partner). For example, if in a single project, academic partners felt that all partners were involved in deciding on research questions to address whereas community partners did not feel they played a role in deciding on research questions, there would be clear dissonance between how partners perceived the process of selecting research questions, and that is important. Because CBPR is an approach that values equal decision-making power at every step in the research process, it is problematic when one set of partners' reports that this is not happening without the other set of partners being aware that the problem exists. Once such themes were determined within projects, only then could I look across projects to see the degree to which such patterns were unique to a particular dyad or common across dyads.

In order to increase the validity and reliability of all qualitative findings, memos and a journal that document the coding process were kept within the NVivo9 program. Memos help coders to reflect on the data analysis process and to maintain a record of developing codes and themes. When a summary of themes was generated, a group of randomly selected partners were sent transcribed portions from their interviews with the corresponding codes developed during the analyses described above. Partners were asked to confirm whether the coding accurately represented their ideas. In some instances, this process lead to an extensive exchange of ideas between partners and me to ensure the validity of reported findings. This process is referred to as "member checking" (Minkler, Vásquez-Brechwich, Warner, Stuessey, & Facente, 2006, p. 294; Tajik et al., 2008).

Human subjects review. This protocol was submitted to and approved by the Social & Behavioral Science Institutional Review Board (IRB) at the University of Wisconsin – Madison (approved protocol number SE-2011-0815). The informed consent form for this study is included in Appendix C.

Overview of the Organization of Dissertation

In this dissertation, I examine the process of investigating and addressing the social determinants of health in ten CBPR projects, as well as examine the role of empowerment in community-academic partner dyads in these ten CBPR projects. The findings from this study are presented in three separate papers. The first paper employs content analysis to consider the factors that facilitate and inhibit investigating and addressing the social determinants of health using a CBPR approach. The second paper uses dyadic analysis to compare perceptions of academic and community partners who worked together on the same project to help determine whether or not a CBPR process is perceived to be empowering by both partners. The third paper is aimed at a non-academic audience. It uses results from the larger study to provide practical suggestions for community partners interested in engaging in community-academic partner research that is empowering and meaningful to their communities. In a final section, I integrate and discuss the three papers, as well as share implications for the fields of social work and CBPR. It is important to note that throughout this dissertation, specific details of the partnerships are deliberately absent. This was done to maintain the confidentiality agreements between respondents and researcher as set forth by the University of Wisconsin, Madison IRB.

PAPER 1

FACTORS THAT FACILITATE AND INHIBIT INVESTIGATING AND ADDRESSING THE SOCIAL DETERMINANTS OF HEALTH THROUGHOUT A CBPR PROCESS

Abstract

Objectives. This article examines factors that promote or inhibit investigating and addressing the social determinants of health (SDH) throughout community-based participatory research (CBPR) processes.

Methods. Purposeful snowball sampling was used to identify 10 CBRP partnerships that were identified as successful in investigating and addressing the social determinants of health. Semistructured interviews were conducted with academic and community partners from each partnership.

Results. Findings indicate that there are several factors, such as political support and partnership characteristics that promote investigating and addressing the SDH throughout a CBPR process. Factors that inhibit investigating and addressing the SDH in a CBPR process include historical trauma and low socioeconomic status of the partnering community, as well as the current political climate.

Conclusions. Lessons learned throughout this study suggest that considerations of local political leanings and social conditions may be important to investigating and addressing the SDH. CBPR practitioners are urged to consider the role of SDH in all CBPR studies of health and health disparities.

Introduction

Health Disparities

Health disparities disproportionately affect racial and ethnic minorities in the United States (U.S.) and are large and persistent over time (Syme, 2008; Williams & Mohammed, 2009). Racial and ethnic minorities often have high rates of chronic health conditions including cardiovascular disease, kidney disease, stroke, diabetes, hypertension, liver cirrhosis, and cancer (Kung, et al., 2008; Syme, 2008; U.S. Department of Health & Human Services, 2009). In addition, several minority groups experience higher rates of disease and death for most conditions (Williams & Rucker, 2000).

These alarming differences in health may be fueled in part by disparate access to, or substandard, health care (U.S. Department of Health & Human Services, 2009). However, health disparities can also be explained by variation in several broad *social determinants of health* (SDH) such as educational attainment, poverty, environmental factors, culture and social support (Dressler, 2004; Mays, et al., 2002; Niederdeppe, et al., 2008; Robert & Booske, 2009; Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; Williams & Jackson, 2005; World Health Organization: Commission on Social Determinants of Health, 2008). Indeed, SDH are associated with disparate health outcomes in ways that extend beyond individual-level health behaviors and practices (Israel, et al., 2010).

Community-Based Participatory Research

One approach that has been used to explore causes, consequences and remedies for health disparities is Community-Based Participatory Research (CBPR). The use of CBPR is well-documented in engaging ethnic and racial communities in research that reflects the concerns of local residents (Israel, et al., 2001; Israel, et al., 1998; Potvin, et al., 2003; Rios, et al., 2008). This model is characterized by a partnership-driven approach to community change that ideally fosters empowerment, equity, respect and shared responsibility among all members of the research team. CBPR builds on local strengths and resources in pursuit of community improvement and wellbeing (Israel, et al., 1998).

Through active collaborations and shared expertise, researchers and community members work to achieve greater knowledge of a given phenomenon, which then benefits the health and well-being of involved communities (Israel, et al., 2001). CBPR partnerships experience "success" when they complete goals that are identified by the community while also helping to advance science around topics studied (Israel, et al., 1998; Potvin, et al., 2003; Rios, et al., 2008).

In particular, CBPR is well situated to address social problems posed by disproportionately high rates of poor health in racial and ethnic communities.

Limitations of community-based participatory research. Despite the versatile and empowering nature of this approach, many CBPR projects do not address the multiple levels at which SDH arise and operate. Rather than considering the larger social conditions that foster health disparities, as well as multilevel solutions, many CBPR studies focus exclusively on changing public attitudes and opinions around specific topics, for example, negative attitudes toward cancer screenings, or changing individual health behaviors such as incorporating daily exercise. Such an individual-focused approach risks "victim blaming" as well as overlooking the source of health disparities (Israel, et al., 1994; Kannan, et al., 2009). While these uses of CBPR may have short-term effects on health, such efforts may not be sustainable, may not benefit future community cohorts, and may not address the broader social factors that affect larger or sustainable health changes (Schulz, Krieger, & Galea, 2002; Syme, 2004).

The lack of attention to SDH at multiple levels in much of CBPR work may be due to the potentially long-term commitment necessary to see the impact of these efforts within an already complex research process. CBPR projects may take months or years to fully develop, during which time community and academic partners may lose motivation, turn their attention to other projects or commitments, or experience any number of other interruptions that disallow progress (Wallerstein & Duran, 2006). Questions surrounding the availability and affordability of local resources such as community members with the time and desire to address local problems, as well as the perceived importance of health in light of other more pressing problems, are constant struggles. As such, the primacy of empowerment and community determination in CBPR

projects may result in communities choosing more proximate and tangible issues and solutions to address rather than those that are long-term in nature (Israel et al., 2008; Schulz, et al., 2005).

Attending to more immediate needs that communities present is not problematic per se. On the contrary, CBPR partnerships thrive on the ability to respond to the unique and diverse problems that communities present. However, addressing pressing issues does not preclude taking further actions to consider how and why social factors have contributed to such problems in the first place. For example, if a community reports street violence as a pressing issue, an important first step may be to install ample street lighting and petition local government to fund additional police reinforcement. However, once such efforts are in place, an important next step is to consider why violence has been occurring in the first place. For example, do high rates of local unemployment foster unrest and violence? Are there limited affordable and safe social activities in the community? Considering these and other social factors is important in understanding why a phenomenon exists (in this example, high rates of street violence). To promote sustainable change, it is important that solutions seek to mitigate the roots of social problems rather than simply moving or displacing them.

At times, CBPR practitioners have neglected their role in addressing health impacts at multiple social levels, especially given the aforementioned challenges (Kreuter, Lezin, & Young, 2000; Minkler & Wallerstein, 2008b). There is, however, a smaller subset of CBPR studies that *do* investigate and address the SDH to varying degrees. Thus, questions emerge as to how such partnerships have been able to successfully attend to these social factors in light of competing demands and issues. In order to help answer this question, this study examines the facilitating and inhibiting factors described by ten CBPR partnerships that have investigated and addressed the SDH in their work.

In this paper, I will first provide background information about how CBPR partnerships were identified for this study. Next, I will discuss the process by which CBPR partnerships were recruited and interviewed. I will then discuss how data were analyzed using a qualitative content analysis. I will summarize findings concerning factors that facilitate and inhibit investigating and addressing the SDH within CBPR partnerships. I will conclude with lessons learned from this study that may be useful for future CBPR partnerships interested in investigating and addressing the SDH. The study was approved by the University of Wisconsin, IRB. Per the confidentiality agreements between respondents and researcher set forth by the University of Wisconsin, Madison IRB, specific details and contextual factors about the partnerships are deliberately absent so that they cannot be identified.

Methods

A preliminary investigation was conducted to identify and review CBPR studies that were successful in investigating and addressing the SDH to various degrees. In order to be included in this review, studies needed to satisfy the following five criteria (adapted from Minkler et al. (2008)).

1. Demonstrated excellence in the CBPR process, defined as living up to the core principles of CBPR practice (as described by Israel and colleagues (1998)).
2. Took steps to investigate and address the SDH in CBPR processes. This criterion refers to whether authors incorporate the SDH into their research questions, goals, framework, actions, etc.
3. Demonstrated a clear commitment to improving the public's health and promoting health equity.
4. Featured research in partnership with low-income, racial/ethnic communities in the U.S.

5. Was featured in a publication from the last 5 years.

An extensive review of literature yielded eight CBPR studies that met all five inclusion criteria.

Data Collection

The eight identified partnerships served as an initial sample for the current study. All eight partnerships were contacted by email and/or telephone, with four agreeing to participate in the study. These four partnerships suggested an additional six partnerships that shared similar goals of investigating and addressing the SDH and that adhered to the inclusion criteria. This referral method of recruitment is called *purposeful snowball sampling* (Miles & Huberman, 1994). In order to be included in the present study, at least one academic partner and one community partner per project needed to agree to participate in a semi-structured interview.

In preparation for the interviews, academic partners were asked to refer me to any publications, community reports, grant applications or other background information about the projects in order to orient me to the project before the interviews took place. Partners were mailed a copy of the informed consent form with a postage paid return envelope. Partnerships that agreed to take part in the study participated in an approximately one hour recorded telephone or Skype interviews. Academic and community partners were interviewed separately in order to create an environment in which they could speak freely and voice confidential concerns if necessary. Partners were asked a series of interview questions concerning their work on the identified CBPR project, with emphasis on the factors that inhibit and facilitate investigating and addressing the SDH.

Data Analysis

Digital recordings from the interviews were professionally transcribed verbatim and checked for accuracy upon receiving the completed transcripts. Next, a qualitative content

analysis – a methodical, empirical technique – was used to analyze text within and across interview data (Mayring, 2000). The qualitative content analysis consisted of the following steps: First, hard copies of the interview transcriptions were reviewed by me and a second coder using an unrestricted *open-coding* process, which is used to inquire broadly and to identify emergent themes from the raw text (Berg, 2004). For the purpose of this analysis, the coders approached the data with the intention of understanding what factors facilitate and inhibit addressing and investigating the SDH within a CBPR process. Narrowing the focus of our analysis was guided by questions in the interview protocol, a process common in initial stages of coding (Coffey & Atkinson, 1996); however, beyond these constraints, the coders were not limited in their analysis.

At the end of the open-coding process, both coders convened to compare codes in order to increase the reliability and validity of findings, and a preliminary list of themes was compiled. Next, I imported interview transcripts and the preliminary list of themes into NVivo9 qualitative data analysis software (QRS International, 2010) in order to assist in recoding. Recoding helps ensure that themes were not overlooked in the open-coding process and also allows for further revision and development of themes. The second coder did not participate in the recoding process but did meet with me to review findings.

Themes that emerged from the analysis were "named by the researcher, to include a variety of ways that respondents express an underlying concept" (Lacey & Luff, 2001). For example, the theme "academic partner characteristics" (detailed below) emerged from academic partner responses suggesting a self-proclaimed and/or recognized orientation toward and experience with CBPR and the SDH. In one case an academic partner noted:

> You know I'm a public health physician. Public health is the profession that tries to prevent disease, so I see working with communities as part of my job. It's part of what I should be doing, what I do regularly, what I've done for a long time and continue to do.

In another case, the academic partner said that he and another academic partner had "been here at the university together a long time, engaging with immigrant community organizations on occupational health issues". In both instances, the academic partners demonstrate a long-term commitment to community-based research.

In the case of the above described theme, as well as all of the themes described in this paper, themes were developed by considering whether there was repetition of ideas and concepts across interviews. Ultimately, it is at the discretion of the coders to decide how many times a concept need be repeated to be considered a theme (Ryan & Bernard, 2003); however, in order to increase the validity and reliability of the findings for this study, several measures where taken. Interviews were recorded so that the coders could re-listen to *how* respondents discussed their ideas in addition to what ideas where expressed. Memos and a journal that documented the coding process were kept within the NVivo9 program. Memos and journaling help coders to reflect on the data analysis process and to maintain a record of developing codes and themes. In addition, a group of randomly selected partners were sent transcribed portions from their interviews with the corresponding codes developed during the content analysis described above. Partners were asked to confirm whether the coding accurately represented their ideas. In some instances, this process lead to an extensive exchange of ideas between partners and me to ensure the validity of reported findings. This process is referred to as "member checking" (Minkler, et al., 2006, p. 294; Tajik, et al., 2008).

Results

Findings from interviews with both community and academic partners in ten CBPR partnerships suggest that there are several factors that facilitate or inhibit investigating and addressing the SDH throughout the research process. While the majority of partners discussed well-established aspects of CBPR partnerships as facilitative, such as open communication and trust between partners (Israel, et al., 1998), the factors outlined below are those that partners say were particularly influential to investigating and addressing the SDH throughout the CBPR process. For each theme, counts are included to indicate how many of the ten partnerships were in agreement concerning that particular factor.

Facilitating Factors

Partnership characteristics. Throughout the interviews, partners suggested that there were two characteristics of the partnership that contributed to their ability to investigate and address the SDH throughout their projects: 1) an overt shared commitment to investigating and addressing the SDH by the partners and 2) a long-term relationship as a partnership. The first characteristic was described as a shared dedication to understanding the specific SDH that operated in the partnering community, such as the global transport of environmental toxins that decrease air and water quality or the displacement of community members from their homes. To better understand the specific factors that affected health in the partnering communities, academic and community partners had multiple conversations to ensure that there was a clear understanding of the main issues affecting the health of the community. In addition, surveys, interviews and focus groups were utilized to gain direct feedback about issues that lay community members felt were important to study. By gaining a rich understanding of the factors that affect health in the partnering communities, partners entered their studies with a clear sense

of which SDH were of particular importance to investigate and address throughout the CBPR process.

The second characteristic was described as relationships that developed over many years. Four of the partnerships interviewed had worked together for over ten years, and another five partnerships had worked together for at least five years. Five partnerships also noted that they had worked together in other capacities before coming together on the current project. Partners say that, over time, they developed a deep level of trust and comfort with each other. In addition, long-term partnerships allowed projects to morph and grow from addressing individual needs and behaviors to addressing the broader SDH that help explain health disparities. For example, one partnership discussed how the initial purpose for their work was to address issues related to obesity and well-being. The program began with a focus on exercise and nutrition, with success measured in large part by pounds lost. Over time, partners learned from participants in their study that another important correlate of obesity in their community was a lack of jobs, which led to eating to distract from the pain and fear of unemployment. As such, the program took a new direction to consider the issue of economic empowerment and the need for local jobs that would help address the issues of health over time. In this example, as in others, it became apparent that time and the willingness to incorporate feedback made partnerships better able to investigate and address the social factors that influence health in the partnering community.

Academic partner characteristics. Partners agreed that there were many characteristics specific to the academic partners that facilitated successfully investigating and addressing the SDH. In particular, seven of the academic partners had a self-proclaimed and/or recognized orientation toward and experience with CBPR and the SDH in the past, often having worked on

other projects of this nature. For example, one of the academic partners described another one of the academic team members as:

> a global health guy for a long time before global health was cool. And he's done lots of work throughout mostly throughout Latin America...And I think through that work, he was very oriented towards the social determinants.

Some partners note that such international experience also fostered a deeper understanding of the social factors that contribute to health, especially when partnering with immigrant communities.

In addition, seven of the academic partners had a long history of working on the specific SDH investigated and addressed in the study, which included such topics as workplace health and safety, economic empowerment and combating environmental injustice. Over the years, two academic partners became involved in local community organizations that address these issues, later partnering with those same organizations in the current projects. Seven of the academic partners had worked in the same local region of the U.S. for many years, experiencing development and change within the partnering community. As such, one community partner noted that, "they [the academic partners] really know the whole complex structure in – how, you know how that community gets here and what are their needs? You know the dynamics of [the population served in the project], they understand from any angle". This deep level of understanding and commitment to the communities they partner with appears to assist academic partners in investigating and addressing the deeply rooted factors that influence health in the community.

Community partner characteristics. Six of the partnerships reported that the community partner had a history of active participation in different levels of government and, subsequently, could help influence policies that are pertinent to findings from their respective

partnerships. For example, one of the community partners was a member of the mayor's health task force. In this role, the partner increased the partnership's access to and influence on local legislation. In addition, seven of the partnering community organizations had a long history of activism and other political activity in the communities that helped to rally community members around issues of concern and helped to give voice to marginalized community members. Just as many of the academic partners often had experience studying the SDH, seven of the community partners had experience advocating for social change that affects the health of their communities. Such experience may help to explain their willingness and capacity to investigate and address the SDH at multiple levels, rather than focusing on individual-level change.

In addition, all partners noted that the organizations where community partners were affiliated have "their finger on the pulse" of all things community related, including the specific SDH that influences the health of community members. This was especially true for community partners who lived in the communities that they were serving on the project, who had helped form the community organization that they represented in the project, and who worked with a wide range of other community partners that represented the community. In six of the partnerships, the partnering organization had already been investigating and addressing the issues that the CBPR partnership studying, from issues related to contamination of air, water and soil to wage theft encountered by low-wage workers before the projects ever began.

Finally, three of the partnerships noted the importance of the community partners as a bridge between community members and the academic partners, and the role this played in investigating and addressing the social factors that influenced health in the community. One of the academic partners commented that her community partner:

> had a foot in both worlds, she was a founder of [the partnering community organization], still very active with them and very respected by academics on our campus, just beloved in the community and among practitioners. So she was a great logical link person between the [partnering community organization], the Health Department and the academics.

With a heightened understanding of the issues concerning community members, as well as the capacity to translate those needs to the academic team, community partners that served as bridges between the community and academic partners helped the team to focus on the specific SDH in the community that influence health.

Government and political support. Four of the partnerships discussed the importance of governmental support through specific departments and agencies, such as The Department of Public Health and The Occupational and Health Administration (OSHA), as well as support from individual elected officials. Governmental support was provided by different levels of government (i.e. city, regional, state and national). Three partnerships discussed the benefit of a supportive city-level government that valued the research of the partnerships both by incorporating recommendations and findings from the partnerships into city policies, and by publically announcing the importance of the research being conducted. Helping government officials understand the extent to which SDH influence health disparities was accomplished by providing tangible evidence through data, field reports, as well as tours of the communities. Investigating and addressing the extent to which health disparities were operating in the communities was crucial in arguing why additional legislation, enforcement and/or resources were necessary to confront the issues studied by the partnerships. Partnerships that worked closely with city officials described the benefit of sharing their work around the SDH. One academic partner noted:

> the large Mayor's Health Taskforce made a committee just for our project and gave us as much time as we wanted. You know whenever – to be a part of the Mayor's Health Task Force and recognize that this is an issue for the community; workplace health and safety. I've never encountered – I mean people work on everything on that committee from dental health to you know general men's health and smoking and obesity and everything. In fact the other day we went to the Environmental Health Committee and its new for people but it's not like they feel that I shouldn't be there. It seems – people recognize that it definitely is a concern in the community and a need of the people …

In this example, the partners described the validation and benefit of working with elected officials that valued social factors that influence health, even if this perspective on health did not fit within a health paradigm commonly discussed at the city level.

Work with regional, state, and national sectors of government were also noted as being important in investigating and addressing the social factors that influence health in communities. At the regional level, three partnerships worked with OSHA officials around issues of workplace health and safety. These partnerships noted the importance of partnering with OSHA in communities with large immigrant populations where language barriers and potentially dangerous work conditions created an environment in which health could easily be compromised. Working with regional administration and staff members helped both to educate the agency and to influence the ways in which the agency worked with the partnering communities.

At the federal level, two partnerships presented the work of their partnerships in Washington to demonstrate the health disparities that operate in the communities, as well as to provide evidence suggesting that social and environmental factors contribute to these problems. Partners said having data from their partnerships was crucial in educating legislators about the health issues in their communities in a credible manner. Government support was helpful in addressing the social factors that influence health in communities due to the power and authority

held by such systems and individuals. One academic partner commented that "every researcher should have some level of government involved in their grant", as change makers exert great influence in the lives of community members.

Inhibiting Factors

In addition to factors that facilitate investigating and addressing the SDH throughout the research process, partners also described a number of inhibiting factors. As was true of the facilitating factors, the majority of partners discussed well-established inhibiting factors – or challenges – within CBPR partnerships, such as differences in timelines and/or understanding of time, insufficient project funding, problems retaining partners, turnover in community and academic institutions and unequal power between partners (Israel, et al., 1998). Below, factors that partners say were particularly challenging with regard to investigating and addressing the SDH throughout the CBPR process are discussed.

Lack of government and political support. While four of the partnerships discussed some of the ways in which government and political officials supported the work of their partnerships, another four of the partnerships mentioned the ways in which these institutions and individuals inhibited this work. In three instances, partnerships noted that, at times, members of governmental programs, such as the Department of Housing and Urban Development (HUD), the US Army Corps of Engineers, and OSHA were unresponsive to requests from the partnerships with regard to participation, support and action. For partners concerned with specific SDHs, such as housing, limited access to and support from government programs, such as HUD, inhibited the extent to which the partnership could investigate and address the impact of public housing on health.

Members of one partnership noted that these issues were compounded for undocumented populations for which funding was extremely limited. Four of the partnerships felt that some government programs did not adequately enforce laws and standards set forth by their governing policies, as it concerned such issues as job safety and proper monitoring of air and water contamination, for example. Three partnerships also suggested that the government, as well as academic institutions, were largely swayed by the contributions of large industries, such as the industrial hog producers and private urban development companies, which made large financial contributions, thus being allowed to perpetrate structural, social and environmental injustices. As such, many partners felt that the government would not support work that would threaten the relationships with these industries lest they compromise financial support. This is problematic, of course, when partnerships were trying to address the very social and environmental factors that were compromised due to the practices of such industries.

Historical trauma. Four partners discussed historical traumas that adversely impact present-day CBPR work in investigating and addressing SDH in communities. One example that was mentioned was the infamous Tuskegee Syphilis Experiment, in which African Americans were systematically betrayed and dishonored by the U.S. government in the name of "science". In other instances, partners discussed a high degree of fear and resistance of community members to become civically engaged in issues that directly affect their health, and for good reason. One community partner eloquently summarized this dilemma:

> … the history of institutional racism and prejudice makes it very hard for us people to speak or to become involved in any kind of a social movement... there's not much organized opposition to environmental racism or to institutionalized racism of any kind or economic injustices or injustices from the Sheriff's Departments and banks and all the stuff that's going on. There's not a lot of resistance because people are afraid. And you know, rightly so. And they don't have very many resources. They don't want to compromise

> what they've got. So that's a huge barrier to doing anything and in fact, that's the problems that we're studying there in the first place.

As discussed in the above quote, historical mistrust of institutions and individuals in power fosters a fear of engagement and action. This statement is not meant to blame or penalize individuals for their response – or lack thereof – rather it helps to explain why communities may be less likely to become civically engaged. As one community partner explained, "their [community members'] ability to become activists is compromised by diseases that affect people of color and low income in our country weighing more than privileged people." This strained ability to participate to the same extent as others who exert more power due to race or socioeconomic status may contribute to a loss of community as a source of power and strength (Putnam, 2001) and further supports the need for CBPR partnerships to tackle these fundamental SDH in their work.

One community partner also discussed historical friction within the partnering community, between neighbors and leadership. These tensions were in part a reaction to local social and structural factors, such as redevelopment and relocation of families. As such, it was difficult to get connected to long-time leaders in the communities due to tension, lack of trust and fear of others outside of tight networks within the community. Regardless of the perpetrator, it appears that historical traumas within – or imposed on – communities are detrimental in terms of examining the very socioeconomic, racial and structural damage that adversely affected the health of communities to begin with.

Anti-immigrant climate. Half of the partnerships partnered with immigrant communities. Three of these projects investigated and addressed the role of workplace environment and safety on health. These studies often focused on immigrant populations that came to the U.S. in search

of the opportunity to save money to send back to their families abroad, and/or to improve their quality of life. As a result, such communities were more likely to work long hours in unregulated and unlicensed working conditions, often risking their health and well-being in return for increased financial stability. However, in an anti-immigrant climate, partners suggest that there was less concern for the needs of such communities and poor oversight of workplace policies and practices, thus making it difficult to address the poor working conditions that adversely affect immigrant worker health. Overall, investigating and addressing broader SDH, such as working conditions and workplace policies, was accomplished by these CBPR partnerships; however, this work was made more difficult by the anti-immigrant climate.

While some barriers, such as language differences between partners, were more easily and thoughtfully addressed within partnerships in this study, a larger political and social anti-immigrant climate proposed several barriers to others. For example, four partnerships mentioned that government programs did not provide adequate information in linguistically and culturally appropriate formats for community members nor did they value local input in understanding and solving local problems. Members of one partnership discussed how grants and/or government funds were not available for immigrants – especially those who were undocumented. As one community partner noted:

> Well you know there is the nature of the patients and the community that we serve, which is a very sensitive issue, which is immigration status. I mean it's people that are here, but not really here, but they're here but they don't exist. I mean for programs like this to approach for example, a foundation, it's like 'and you are helping who?' So that's definitely another challenge but even within our community, they're technically non-existent.

Beyond limited support from government and foundations, partners also described a lack of awareness in several communities about the critical role of immigrant populations, such as

vital contributors to the workforce. However, with a strong need to work and support their families here and abroad, immigrant workers may be susceptible to poor working conditions, and subsequently, poor health outcomes (Minkler et al., 2010; Roelofs, Sprague-Martinez, Brunette, & Azaroff, 2011; Siqueira & Jansen, 2011). As such, the work of CBPR partnerships that investigate and address the social and economic conditions that perpetuate poor health in immigrant populations is crucial to confronting these disparities.

Discussion

In this study, several factors were found to facilitate and/or inhibit investigating and addressing the SDH. In this section, I will summarize lessons learned for this work, discuss limitations and suggest a call to action for CBPR practitioners.

Findings from this study suggest that characteristics of successful CBPR partnerships that investigate and address the SDH might be facilitated by a long-term shared commitment to this work. Due to the complex nature of health disparities, and the process by which partnerships address them, partners are encouraged to consider the extensive time commitment to adequately address these issues (Israel, et al., 2008).

In addition, findings suggest that community partners (and partnering organizations) that are skilled at policy and advocacy work play a critical role in investigating and addressing the SDH. Politically active community partners may help increase the partnership's access to and influence on local legislation. As Jones and colleagues (2010) discuss, CBPR has the capacity to inform political change by building on tools and resources that communities already possess. One way that CBPR partnerships might consider strengthening the role of community partners in addressing policy is through networking with a variety of community organizations and other systems, such as public health departments and school boards, to address issues as they emerge.

A diverse group of partners – often referred to as a community advisory board (CAB) – may offer a holistic and comprehensive approach to addressing health in communities (Newman et al., 2011).

There are several factors that may inhibit the work of CBPR partnerships seeking to address the SDH. Communities that have experienced extreme historical trauma, betrayal and oppression, both institutionally and by the research community (e.g. Tuskegee Syphilis Experiment), may be less inclined to participate in research. As Wallerstein and Duran (2008) suggest, CBPR practitioners bear the responsibility of learning about this complex history, which may help to explain a mistrust of their presence in communities, as well as potential hesitance for involvement. If not, "they might be denied entry or have their research undermined through overt or hidden forms of resistance" (Wallerstein & Duran, 2008, p. 31).

In addition, CBPR partnerships are encouraged to consider why, and under what circumstances, immigrant communities may experience a disproportionate burden of poor health. Dangerous working conditions and/or inconsistent compensation may be tolerated by immigrants in order to support families here and abroad. A willingness to accept poor working conditions may also reflect an anti-immigrant climate in which few social or financial benefits are available, thus necessitating work in conditions that are potentially hazardous to health (Siqueira & Jansen, 2011). Thus, social conditions, such as the workplace environment, appear to be particularly crucial to consider when investigating and addressing the health of immigrant communities.

Finally, government and political leaders may or may not support the work of CBPR partnerships that address the SDH, depending on the political sensitively of the topic at hand; availability of data to demonstrate the severity of the problem; availability of appropriate governmental services and resources to address the topic (e.g. public health, law enforcement

and HUD); influence of external funding sources (such as private corporations) and willingness and responsiveness of government officials to publicize and incorporate recommendations and findings from partnerships. As suggested previously, developing a CAB that includes stakeholder in government may help partnerships to advocate for policy change (Newman, et al., 2011).

One limitation of this study is that only partnerships that overtly investigated and addressed the SDH were invited to participate, which disallows a comparison of partnerships that do not investigate and address the SDH. However, for this exploratory study in which little has been reported about the intersection between SDH and CBPR, the main focus was to gather information about those CBPR partnerships that *do* investigate and address the SDH. Additionally, conducting a truly exhaustive search of CBPR studies that investigate and address the SDH proved difficult, as the broad nature of SDH means that many diverse disciplines incorporate this framework, whether they refer to it specially or not. For this reason, snowball sampling methods proved valuable in identifying studies across disciplines that might otherwise have been difficult to locate. Finally, issues of memory bias, which can alter recall of events, people, place etc., may have influenced the content of partners' responses.

Despite these limitations, this study demonstrated that there are several factors that may promote and/or inhibit investigating and addressing the SDH through a CBPR process. These findings might be useful to other academic-community partnerships seeking to address health and health disparities at multiple ecological levels that extend beyond individual-level change. Indeed, an important next step in advancing the field of CBPR is for *all* studies that use this approach to at least consider how and why SDH play a role in creating and maintaining health disparities.

This proposition is not meant to discredit a rich history of accomplishments experienced by CBPR practitioners; rather, it is a bold call to action. Despite years of research and investigation, differences in health across racial and ethnic groups persist, in part because we have yet to thoroughly investigate and address the social, economic and political conditions that give rise to these disparities. Given our increasing understanding of how the SDH influence well-being (Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; World Health Organization: Commission on Social Determinants of Health, 2008), it is time that the field of CBPR responds by taking more active steps to consider how the SDH influence our understanding of health disparities and, eventually, move towards investigating and addressing SDH in all partnerships.

PAPER 2

DIFFERENCES IN PERCEPTIONS BETWEEN CBPR PARTNERS:

A DYADIC INTERVIEW ANALYSIS

Abstract

Background: While the concept of empowerment is a key principle of CBPR, we know little about how academic and community partners each feel with respect to empowerment during a CBPR process, and whether or not there are differences between academic and community partners who work together on the same project.

Objectives: Comparing perceptions of academic and community partners who worked together on the same project can help determine the degree to which a CBPR process is perceived to be empowering by both partners.

Methods: Semistructured interviews were conducted with both community and academic partners in 10 CBRP partnerships. A dyadic interview analysis was used to analyze the dynamics and relationships that transpired within academic-community dyads and across dyads.

Results: Five of the partnerships showed no differences in perceptions with regard to empowerment between partners who worked together on the same project. Four partnerships had minor discrepancies with regard to empowerment. Only one partnership varied considerably between partners, where the community partner appeared less empowered with regard to determining the topic of study, understanding the importance of the topic studied, as well as overall control, influence and respect throughout the research process.

Conclusions: Successful *outcomes* are not the only goal of CBPR, because the *process* of achieving those outcomes, and the relationships built within that process, are also highly valued. Not all projects that are quantifiably successful in their outcomes are perceived to be successful with regard to empowerment throughout the process. Therefore, CBPR projects might evaluate perceived empowerment of partners throughout the process and make changes if necessary.

Keywords: dyadic interview analysis, social determinants of health, health disparities, empowerment, perception, partnerships

Introduction

Community-based participatory research (CBPR) is an approach to research that is characterized by academic-community partnerships that ideally promote equitable sharing of diverse sets of knowledge throughout the research process. CBPR builds on local strengths and

resources in pursuit of community improvement and wellbeing, as well as the advancement of science. Ideally, CBPR fosters a sense of respect, trust, equal decision-making and empowerment among all members of the research team (Israel, et al., 1998; Minkler & Wallerstein, 2008a).

In their classic CBPR article, Israel and colleagues (1998) outline eight key principles of CBPR, noting that this approach "promotes a co-learning and empowering process that attends to social inequalities (p.179)". The importance of creating an empowering research process and outcomes is a repeated theme throughout the CBPR literature (Griffith et al., 2010; Israel, et al., 1998; Wallerstein & Duran, 2006), where empowerment refers to the process by which individuals, organizations and communities gain control and influence over conditions in their lives (Fawcett, et al., 1995; Rappaport, 1987).

While the idea of empowerment resonates with many CBPR practitioners, questions remain concerning our actual knowledge of how partners feel with respect to empowerment during a CBPR process. For example, do community and academic partners view various aspects of the research process to be empowering or disempowering? Do partners have similar or different experiences of empowerment throughout this process? Such questions appear to be critical in advancing our understanding of empowerment as a key component of CBPR practice and scholarship.

The concept of empowerment takes a strength-based approach to working with communities that compels us to see community members as local experts capable of addressing the social problems that they confront in their daily lives (Perkins & Zimmerman, 1995). Like CBPR, the concept of empowerment is influenced by the work of Brazilian educator Paulo Freire (Freire, 1970) and reflects similar values including collaboration, reciprocal relationships, a participatory learning process and power sharing (Fawcett, et al., 1995; Freire, 1970; Maton &

Salem, 1995; Rindner, 2004). The very nature of the relationships developed within an empowerment-based research process foster confidence and agency for those involved and may also enhance the richness and depth of the research process (Fawcett, et al., 1995; Freire, 1970; Rindner, 2004).

In addition, the concept of empowerment emphasizes both an empowering research *process,* as well as empowering *outcomes* (Perkins & Zimmerman, 1995; Wallerstein, 2006). An empowering process refers to "intentional, informed participation, aimed at affecting change" (Becker, et al., 2002, p. 700). Empowering outcomes refers to the power that is developed through this process and that can then be used to satisfy needs and to affect social change.
In this paper, I will first provide background information about a larger study of CBPR partnerships from which this paper emerged. Next, I will discuss the dyadic interview analysis method that was used to examine whether partners on the same projects agreed or disagreed regarding several aspects of their research processes. Next, I will summarize themes from within partnerships, as well as across partnerships. I will conclude with suggestions for future CBPR partnerships concerned with maintaining a research process that is equitable and empowering to all partners.

Background

This paper is part of a larger study concerning CBPR partnerships that successfully investigated and addressed the multiple social factors – or Social Determinants of Health (SDH) – such as the environments in which we live, work and play that influence health and health disparities in low-income racial and ethnic communities in the U.S. In order to be included in the study, CBPR partnerships based in the United States were identified through published literature and then were evaluated for their success at investigating and addressing the SDH throughout the

research process. After identifying 10 partnerships that fit these criteria, I interviewed at least one academic and one community partner from each CBPR team. The study was approved by the University of Wisconsin-Madison IRB. Per the confidentiality agreements between respondents and researcher set forth by the University of Wisconsin-Madison IRB, specific details and contextual factors about the partnerships are deliberately absent so that they cannot be identified.

This study examines similarities and differences in perceptions *within* academic-community partnerships for partners that worked together on the same project, and then compares results *across* partnerships. The purpose of considering differences in perception across partners that worked together on the same CBPR project is twofold. First, it is important to assess whether CBPR projects adhere to the principles of empowerment throughout the research process, as is so highly valued among CBPR practitioners. Second, it is necessary to separate whether research partnerships are successful with regard to achieving positive outcomes – in this case, investigating and taking action to address the SDH – versus whether they are successful in developing an empowering research process. In other words, it is possible that CBPR projects can produce important findings and outcomes without engaging in a research process that is mutually beneficial to all partners. Ideally, CBPR projects will do both.

Methods

I conducted a *dyadic interview analysis*, a method that assists in analyzing the dynamics and relationships that transpire between individual members of a dyad, or pair, as well as their shared meaning of a particular phenomenon (Eisikovits & Koren, 2010). For the purpose of this study, dyads were interpreted to mean two partners (academic and community) that participated in one CBPR partnership. The partnerships were considered the unit of analysis. Thus, all

partners interviewed for the same project were included in the dyadic interview analysis for that discrete case. Once themes are determined within each case, themes are considered across cases.

The process of conducting a dyadic interview analysis begins in the same manner as a standard content analysis, seeking to identity consistent themes across text (Berg, 2004; Mayring, 2000). However, dyadic interviews analysis specifically examines the *intra-partnership dynamics* in which each partnership is considered a discrete case. This is done by "assessing contrasts and overlaps between the individual versions" (Eisikovits & Koren, 2010), in other words, examining differences and similarities between what is reported by the academic partner and what is reported by the community partner. For example, if in a single project, academic partners felt that all partners were involved in deciding on research questions whereas community partners did not feel that they played a role in deciding on research questions, there would be clear dissonance between how partners perceived the process of selecting research questions.

Assessing Partner Perceptions

Each partnership in the sample was analyzed to assess whether academic and community partners' perceptions of the research process – and relationships within that process – demonstrated agreement or disagreement across six questions asked during the separate interviews. All six questions broadly concerned empowerment which, in this study, means that partners felt that they had control and influence (Fawcett, et al., 1995; Rappaport, 1987) over decisions through the research process, especially as it pertained to investigating and taking actions to address the SDH. The six questions were: 1) How was it decided to focus the project on the specific SDH? 2) When in the research process was it decided to investigate and address the specific SDH? 3) Who raised the issue of investigating and addressing the specific SDH?

4) How did partners decide the specific SDH was meaningful to the partnering community? 5) Was the specific SDH of great importance and concern to the partnering community before working on this project? 6) Were each partner's ideas valued and respected, such that they were able to demonstrate influence and control throughout the research process?

These six questions were chosen for several reasons. First, as previously stated, a crucial principle of CBPR is empowerment, which suggests that all partners are respected and have power, control and influence to guide the course of the research process. While the idea of equal power and the sharing of ideas at each step of the research process sounds good in *theory*, CBPR practitioners are aware that despite our best intentions, in *practice*, the process of engaging all partners in this way does not always happen to the extent that we intend (Carey et al., 2005; Rowe, 2006). For example, in some cases, people and institutions with more power (in this case, the academic partners) assert more control and influence than those with less power (the community partners), leading to a process that is potentially disempowering. As such, this study sought to understand whether *both* academic and community partners perceived that they had control and influence throughout the research process, such that their needs and interests were pursued.

Additionally, CBPR articles often lack detailed discussions about whether/how all partners contributed ideas and expertise at each stage in a research study. Rather, authors fall back on the principle that decisions should be made collaboratively throughout the research process (Israel, et al., 1998) – implying that they were – without outlining how these ideals were actually upheld. Therefore, an important component of this study is to understand whether partners were in agreement about how major decisions were made, and under what circumstance.

In order to compare responses across partners, transcripts and digital recordings of the individual interviews were reviewed for content, as well as the context in which comments were made. While respondents may have verbalized ideas that appear to be in agreement with their partners, nonverbal data, such as tone, pitch, volume, and use of silence are also suggestive of how a respondent perceives a situation (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). Analysis is challenging when what respondents verbalize conflicts with the nonverbal cues that they employ.

With this challenge in mind, I reported each partner's response to the six questions detailed above, as well as whether there were discrepancies between what respondents said and how they said it. As a result, matching partner responses within the same project resulted in one of the following categories: *Agreement* (A), *Disagreement* (D), *Agreement with Discrepancies* (AD) or *Disagreement with Discrepancies* (DD). *Agreement* results when both partners respond to the same question with the same answer and when their nonverbal cues support their verbal responses. For example, when asked – "When in the research process did partners decided to investigate the SDH?" – both partners responded that this process took place *before* the project ever began and nonverbal cues supported their verbal statements. *Disagreement* results when both partners responded to the same question with different answers and when their nonverbal cues supported their verbal responses. In this case, when asked – "When in the research process did partners decided to investigate the SDH?" – one partner responded that this process took place *before* the project ever began and the other partner responded that this process took place *after* the project began and nonverbal cues supported their verbal statements. *Agreement with Discrepancies* occurs when both partners responded to a question with the same answer but nonverbal cues did not support their verbal statements. Here when asked – "When in the research

process did partners decided to investigate the SDH?" – both partners in a dyad responded that this process took place *before* the project ever began but nonverbal cues did not support their verbal statements. For example, partners said that the decision was made before the research process began, but there was hesitation in their voices, repeated attempts to revise their answers and many pauses before they concluded their thoughts, which may suggest that their verbal responses were not a pure reflection of what happened – or how they felt – about the event they were discussing. *Disagreement with Discrepancies* occurs when both partners respond to the same question with different answers but nonverbal cues did not support their verbal statements. For example, when asked – "When in the research process did partners decided to investigate the SDH?" – one partner responded that this process took place *before* the project ever began while the other responded that this process took place *after* the project began but nonverbal cues did not support their verbal statements.

It is important to note that in the three instances in which there were discrepancies between what the respondent said and other nonverbal cues (see Table 1), such determinations were made within the context of the entire interview rather than in a discrete portion of the interview. For example, if throughout the interview, a community partner repeatedly discussed his frustration in working with his academic partner and then concluded abruptly by saying that the partnership was completely unproblematic, there are notable discrepancies. Again, if we were to analyze the discrete portion of text at the end of the interview in which the respondent discussed his contentment with the partnership, we may wrongly surmise that the partnership was satisfactory. Having conducted and recorded all of the interviews, I was able to re-listen to the interviews in their entirety to confirm discrepancies throughout the interaction. It should be noted, however, that this analysis in no way claims to be a rigorous conversation analysis (e.g.,

Maynard and Clayman, (2004). However, without recognition of the discrepancies between what was said and how it was said – especially within the context of the larger interview – the data would likely suffer from greater misinterpretation.

Results

Patterns within Dyads

Findings suggest that of the ten dyads of academic-community partnerships included in the analysis, five sets of dyads (dyad numbers 1, 2, 5, 9, 10) shared perceptions of the research process – with regard to the six questions outlined previously – within their own partnerships. See Table 1 for profiles of all ten partnerships. Findings within these dyads suggest a high degree of agreement with regard to the process by which decisions were made, and by whom, throughout the research process. In addition, these dyads demonstrate mutual feelings of empowerment within their projects as it pertains to shared influence, power and control.

Findings from four dyads (dyad numbers 3, 4, 6, 7) demonstrate some differences in how academic and community partners perceived the processing of partnering on the same project. Dyad 3 shared perceptions with regard to all questions with the exception of question 5 pertaining to the importance of the SDH studied in the project before the study began. In this dyad, the academic partner believed that the SDH selected was of importance to the community before starting the project, whereas the community partner did not think the SDH selected was something that community members thought about before the project; they became interested once provided with information detailing the significance of the problem. Differences in perceptions of a community's interest in a particular topic before beginning a study may speak to how familiar partners are with the needs and concerns of the partnering community. Ideally,

CBPR projects would be responsive to problems that community members believe are relevant (Israel, et al., 1998).

Dyad 4 shared perceptions with regard to all questions with the exception of question 1 pertaining to how it was decided to address the specific SDH within the study. In this dyad, there was no apparent conflict with regard to how the specific SDH was selected (e.g. no verbal or no verbal cues suggesting that either partner was dissatisfied or disempowered by the process of selecting the SDH). The academic partner described the community partners as "very respected by academics on our campus, just beloved in the community and among practitioners", and the community partner described the partnership as one in which "there was this reciprocal, you know, respect". Nonetheless, the academic partner believed that the community had initiated the idea for the study, whereas the community partner believed that the idea for the study was suggested by both the academic and community partners. In this particular dyad, difficulties pertaining to recall of the specific pattern of events (Wight & West, 1999) may help explain difference in the responses between partners, especially as all other questions demonstrate agreement between partners.

Dyad 6 shared perceptions with regard to all questions with the exception of question 6 pertaining to perceived control, influence and respect throughout the research process. In this dyad, partners agreed that all partners had control, influence and respect throughout the research process; still, the community partner noted that she was not initially invited to participate in all aspects of the research process, specifically in regard to budgetary decisions. There was not full disagreement on this point, as the academic partner recognized this conflict in an earlier part of the interview noting that:

> …we had not been very inclusive when we were writing budgets. And you know, part of that was me. I think I had this understanding that you know, we had to do the

> budget and of course, we would talk to them about – you know, how it was done. But they [the community partners] never actually sat down and were in the very beginning of the budget process with us. And so that made it you know, that's very unequal.

However, the academic partner did connect the lack of transparency on budgeting matters to a perceived difference in control, influence and respect as was articulated by the community partner. As discussed by Carol Horowitz and her colleagues (2009), budgetary discussions can be an essential part of a CBPR process, as they serve as vehicles to address "financial inequalities" often inherent to a CBPR process. Thus it is not surprising that community partners would feel that their empowerment was jeopardized when excluded from the budget process.

As was the case with dyad 6, dyad 7 shared perceptions with regard to all questions with the exception of question 6 pertaining to perceived control, influence and respect throughout the research process. In this dyad, both partners agreed that they had control, influence and respect throughout the research process; still, the academic partner noted:

> … there are always issues of how I didn't understand that, you didn't tell me this. You know you try to be transparent but transparency requires a lot of effort as well from all partners and some partners were more present than others. We had sometimes more difficulty communicating with some people.

Despite these concerns, the academic partner's overall assessment of the partnership with respect to shared control and influence was positive.

However, the community partner appeared more concerned with this issue and indicated that the coordination of the partners and activities in the study was lacking. She also commented that her ability to contribute to various aspects of the research project was limited. Her nonverbal cues, such as speaking with a tone of frustration, indicated that she may have been less satisfied with the overall research process, as well as her capacity to influence various aspects of the

study, than her academic partner. CBPR principles emphasize the importance of communication and the ability of community partners to contribute at every step in the research process (Casale & Clancy, 2009), thus it is not surprising that the community partner would experience dissatisfaction if these expectations were not met.

Only one dyad (dyad number 8) had considerable discrepancies with regard to academic and community partner perceptions of the research process. While partners were in agreement about the first three questions, there was considerable disagreement with regard to how partners determined the specific SDH to study, as well as the importance of the SDH before the study began. As mentioned previously, these discrepancies may reflect issues with recall, as well as familiarity (or lack thereof) of community priorities; however, the most striking finding from this dyad was the perceived level of disrespect and limited control and influence experienced by both partners. In the case of the academic partner, he perceived a lack of respect from other academic partners on his team with regard to the credibility of his work, as well as with his ability to influence the study. In addition, he noted that other members of the academic team seemed threatened by members of the community team who raised questions and actively tried to participate in various aspects of the research process. Such a response from the academic team negates the very essence of a CBPR process that is characterized by shared decision making (Israel, et al., 1998). However, the academic partner felt very respected by his community partners with whom he felt the ability to contribute his expertise and build strong relationships.

On the other hand, the community partner struggled throughout the research process to have her time, as well as the priorities of the community, respected. The community partner also noted that members of the academic team seemed threatened when members of her staff tried to provide feedback and to get more involved throughout the research process. Still, the community

partner appeared fiercely dedicated to meeting the needs of the larger community, even at the expense of her own frustration with aspects of the project. She noted that:

> you need to belong to the organization and to be loyal and to be part of what we want to do and to do everything possible to better the organization regardless of how you feel.

While both the academic and community partners felt there were issues with regard to control, influence and respect throughout the research process, one of the most salient ideas expressed by the community partner was her willingness to absolve the academic team members of their mistakes in order to maintain the relationships and status of the partnership. This was because she felt the partnership was beneficial to her community overall, and in the end, felt compromises were made in order to make the research process more equitable and just.

Patterns across Dyads

Patterns across the ten dyads suggest small discrepancies with regard to shared perceptions of the research process, with the exception of dyad 8. In addition, the five dyads that demonstrated differences between partner perceptions revealed discrepancies related to different aspects of the research process. This suggests that there is not one place in particular where differences in perceived empowerment may occur, rather, issues related to empowerment can be actively addressed throughout the entire research process.

Findings from the larger study of these partnerships suggest that the ten partnerships developed over many years (Paradiso de Sayu, 2013b) with nearly half of the partnerships having worked together for over ten years, and nearly all partnerships having worked together for at least five years. Many partnerships also noted that they had worked together in other capacities before coming together on the current project. Interestingly, dyad 8, which experienced the greatest discrepancies, was the newest partnerships in which many members of

the academic and community teams had not worked together in the past. These findings suggest that with time, partners may gain a better understanding of priority issues to address through research, and ideally, develop relationships characterized by trust and respect for one another. Or it could be that those partnerships that last a long time are those that are characterized by a high degree of trust, communication and understanding of different priority interests in the first place.

Discussion

The importance of co-creating a research process that is empowering for all members of a partnership is well established in both the CBPR and empowerment literatures (Fawcett, et al., 1995; Postma, 2008; Wallerstein & Duran, 2006). As discussed, an empowering research experience is one that facilitates both an empowering research *process*, as well as empowering *outcomes* (Perkins & Zimmerman, 1995; Wallerstein, 2006). Thus, consideration of success in terms of achieving positive outcomes is important to consider within the context of the research process whereby partners experience (or do not experience) feelings of influence, power and control. As demonstrated from the findings of this study, not all projects that are quantifiably successful at addressing the SDH are perceived to be successful with regard to empowerment throughout the research process.

There are limitations to this study. For one, not all members of the ten CBPR partnerships were interviewed. In some cases, the actual partnerships consisted of a dozen or more partners. However, I generally interviewed only one academic and one community partner per study, with particular attention to those partners who were influential in addressing the SDH. Speaking with a larger number of partners from each CBPR partnership may have demonstrated greater differences in perceived level of empowerment within the partnerships.

In addition, partners were only interviewed one time. While a thorough review of published articles, grant reports, white papers, community reports, and conference presentations was conducted before interviewing each participant – providing extensive information about the histories and details of each partnership – concerns due to partner recall of details of a project may have resulted in inaccurate data.

Despite noted limitation, the findings of this study provide insight for future CBPR partnerships concerned with maintaining a research process that is equitable and empowering to all partners. First, findings suggest the importance of *process evaluation* throughout a study. Process evaluations are conducted in order to verify whether there are gaps between what a study proposes to accomplish and what is actually happening on the ground while the project is still in process (Welsh, 2006). Often several process evaluations are carried out within a single study as a way to gauge how the project is progressing. This is especially important when a project spans several years, as is often the case with CBPR.

In addition to measuring progress toward project goals, process evaluations can also serve as useful opportunities to assess a variety of ongoing dimensions of the research process (Butterfoss, 2006), including partners' satisfaction with the research process, as well as feelings of empowerment or disempowerment. Indeed, several of the partnerships with noted discrepancies in this study had strong foundations from which to question, dialogue and modify procedures that were problematic for some partners. As such, making time to assess and reflect on these issues, whether through focus groups, surveys, observations or informal gatherings (Welsh, 2006), may have contributed to better outcomes with respect to feelings of empowerment. In fact, many of the partners in the study discussed the importance of regular

meetings, retreats and celebrations to process the work of the partnership, as well as to set new goals.

Partners provided a host of other suggestions that offer practical ways to improve the research process such that all partners feel empowered. These suggestions included ways in which to establish equitable rules and procedures for the partnerships; ideas for how community partners can take an active role in developing project questions and goals; and mechanisms to encourage ongoing feedback and constructive criticism. For additional suggestions, see (Paradiso de Sayu, 2013a).

Findings from this study suggest the importance of understanding whether or not all partners in a CBPR project perceive the research process to be empowering. Even CBPR projects that appear to be successful in terms of accomplishing their goals can be lacking in terms of maintaining a process that is positively perceived by all partners. An important next step is to investigate whether or not greater feelings of empowerment by all members of a CBPR partnership may actually improve outcomes with respect to project goals.

Table 1

Partnership Profiles

	1: How Decide to Address Specific SDH?	2: When Decide Specific SDH?	3: Who Raised Specific SDH?	4: How Determine Specific SDH Important?	5: SDH Important to Community Before Study?	6: Control, Influence and Respect?
Partnership 1	**A**	**A**	**A**	**A**	**A**	**A**
AP Perception	Community members surveyed, selected specific SDH.	Planning period before study began.	Community at large.	Community member survey results.	Yes, has been an issue addressed by several community groups over time.	Yes, encouraged to bring forth ideas and suggestions.
CP Perception	Community members surveyed, selected specific SDH.	Planning period before study began.	Community at large.	Talking with community members and community member survey results.	Yes.	Yes, consensus process where majority rules, all partners have equal voice.

Academic Partner (AP), Community Partner (CP)

Partnership 2	**A**	**A**	**A**	**A**	**A**	**A**
AP Perception	Specific SDH affected community who then approached AP.	Before study began.	Community members and CP.	CP had been addressing specific SDH and its affect on community.	Yes, CP had been addressing specific SDH before project began.	Yes, developed strong, personal relationships that offer support and respect.
CP Perception	Specific SDH affected community who then approached AP.	Before study began.	Community members and CP.	CP had been addressing specific SDH and its affect on community.	Yes, CP had been addressing specific SDH before project began.	Yes, all partners have equal power in the research process – no hierarchy.
Partnership 3	**A**	**A**	**A**	**A**	**D**	**A**
AP Perception	AP studied specific SDH and approached CP about addressing topic together.	Before study began.	CP first raised issue of addressing specific SDH.	CP had previous experience and interest in specific SDH, felt it was a pressing issue in community.	Yes, community members had been addressing issue before project began.	Yes, external evaluator hired to provide feedback in neutral way. Multilingual meetings.
CP Perception	AP identified specific SDH and approached CP to collaborate on project.	Before study began.	CP first raised issue of addressing specific SDH.	CP had previous experience and interest in specific SDH, felt it was a pressing issue in community.	Did not approach community before starting project to determine interest in specific SDH, but felt that the statistics were strong enough that community members would support study.	Yes, equitable research process helped her to advocate for her fair role in future projects.

Partnership 4	**D**	**A**	**A**	**A**	**A**	**A**
AP Perception	CP approached AP to collaborate in investigating specific SDH.	Before study began.	CP first raised issue of addressing specific SDH.	Community members approached CP with concerns about specific SDH.	Yes.	Yes, felt comfortable bringing up any concerns as they arose.
CP Perception	CP and AP had worked together and developed idea to address specific SDH.	Before study began.	Community at large indentified issue and spoke with CP.	CP had addressed specific SDH in past and collected preliminary data supporting problem.	Yes, CP had been addressing specific SDH for over 40 years before partnership began.	Yes, CP compensated for her time and expertise. 2-way learning throughout research process.
Partnership 5	**A**	**A**	**A**	**A**	**A**	**A**
AP Perception	AP and CP agree on need for services to address healthcare disparities.	Before study began.	AP brought idea to community and was met with support.	Through conversations with AP, CP and community at large.	Community not necessarily oriented to SDH perspective but agree there is a need for intervention.	Yes, able to work through conflict and accommodate one another.
CP Perception	AP and CP agree on need for services to address healthcare disparities.	Before study began.	AP brought idea to community and was met with support.	AP worked in community for years and knew issues, was able to collaborate with CP to address them.	Yes.	Yes, able to share ideas and bring forth concerns. AP very humble.

Partnership 6	**A**	**A**	**A**	**A**	**A**	**AD**
AP Perception	Community members suggested the need to address specific SDH.	After earlier iterations of project that focused on individual determinant of health.	Community members.	Day-to-day conversations and regular meetings with community partners.	Yes.	Yes, mutual appreciation and respect on a daily basis.
CP Perception	Survey data from earlier iterations of project suggest importance of addressing specific SDH.	After earlier iterations of project that focused on individual determinant of health.	Responses from community participation in earlier iterations of the project.	Responses from community participation in earlier iterations of project indicate importance of addressing specific SDH.	Yes.	Yes, community members had an equal voice in decisions; however, at times, needed to reiterate desire to be involved in all stages of project.
Partnership 7	**A**	**A**	**A**	**A**	**A**	**AD**
AP Perception	Community members experiencing health issues related to specific SDH, AP proposed study.	Before study began.	AP with input of CPs.	AP heard complaints from community regarding specific SDH, also through conversations with CP.	Yes.	Yes, but partnership experienced some issues communicating. Did not find issues problematic.
CP Perception	AP had idea, convened partners to discuss specific SDH.	Before study began.	AP with input of CPs.	SDH was of interest to the partners and they agreed to address issue.	Yes, CPs have been addressing these SDH for years.	Yes, but would have liked more input in different aspects of the project.

Partnership 8	**A**	**A**	**A**	**D**	**D**	**AD**
AP Perception	APs worked on specific SDH and wanted to further study of topic.	Before study began.	APs.	APs had interest in specific SDH and wanted to further study.	AP does not think so.	Sometimes did not feel respected by other APs but always by CPs.
CP Perception	APs already had design in place and approached CP to address specific SDH.	Before study began.	APs.	CP had done some previous research in specific SDH and wanted more information.	Health issue was important to community but SDH approach to addressing issue directed more by interests of APs.	Overall yes, but several instances where CP felt disrespected and needed to address these issues.
Partnership 9	**A**	**A**	**A**	**A**	**A**	**A**
AP Perception	Partners were introduced; CP asked AP to help address issue, proposal was created together.	Before study began.	CP.	CP had been addressing for years and asked for help from AP to address specific SDH.	Yes.	Yes, able to communicate well if any issues arise.
CP Perception	Partners introduced, CP had already been working on issue and worked with AP to write grant.	Before study began.	CP.	CP had been addressing for years and asked for help from AP to address specific SDH.	Yes.	Yes, well compensated.

Partnership 10 **AP Perception**	**A**	**A**	**A**	**A**	**A**	**A**
CP Perception	AP and CPs interested in same SDH and were introduced.	Before study began.	AP & CP.	Project partners as well as community members determined issue was important.	Yes.	Yes, feels community members might have been skeptical of her at first but came around.
	AP and CPs interested in same SDH and were introduced.	Before study began.	AP & CP.	Project partners as well as community members determined issue was important.	Yes.	Yes, most balanced partnership CP had ever been a part of.

PAPER 3

THE EMPOWERED COMMUNITY PARTNER:

PRACTICAL SUGGESTIONS FROM CBPR PARTNERSHIPS ACROSS THE UNITED STATES

Introduction

For years, advocates of social justice and health equity have warned the United States (U.S.) that even as the wealthiest country in the world, the health of many of our racial and ethnic communities is in jeopardy. Current research supports these claims. Racial and ethnic communities often experience higher rates of chronic health conditions including cardiovascular disease, kidney disease, stroke, diabetes, hypertension, liver cirrhosis, and cancer (Kung, et al., 2008; Syme, 2008; U.S. Department of Health & Human Services, 2009), as well as higher rates of earlier death for most conditions (Williams & Rucker, 2000), and these health disparities are persistent over time (Syme, 2008; Williams & Mohammed, 2009). Given these trends in health, the question that we must ask ourselves is: What we are going to do to address this problem?

One way to address health disparities is through the use of Community-Based Participatory Research (CBPR). CBPR is a partnership-driven approach to research and community change where community leaders partner with academic researchers to engage and organize communities around issues that affect their health (Rios, et al., 2008). Ideally, CBPR partnerships promote a sense of empowerment, equity, respect, and shared responsibility among all members of the partnership. With dedication and time, CBPR can be useful in addressing the social problems that contribute to poor health among racial and ethnic communities.

While the idea of partnerships between community leaders and academic researchers may seem straightforward – after all, everyone involved is coming together to address issues of health

and social justice – the actual work of CBPR can be difficult to navigate, especially if community partners have not participated in this type of research before. In particular, power dynamics between partners may be challenging, as community partners may believe they have less power. As suggested throughout this guide, community partners have the right to an equal voice in their CBPR partnerships. After all, creating a research process that is empowering to all members of the partnership is a core value of CBPR that is essential to successful partnerships (Israel, et al., 1998). To exercise this right to an equal voice, there are concrete tools and strategies that can be used by community partners in order to get needs and interests met, which are outlined in the following guide.

Using the Guide

The goal of this guide is to provide community partners with background information on how to prepare and participate in CBPR partnerships, as well as to provide tips to navigate relationships with both academic partners and communities at large. Community partners serve as crucial bridges between the communities that they represent and the academics with whom they partner. Academic partners interested in supporting community partners may also find this guide helpful, especially in terms of addressing issues of power – or lack thereof – that community partners may perceive and/or experience.

It should be noted, however, that this guide does not intend to serve as *the* definitive source of CBPR information. There is an extensive CBPR literature that readers are encouraged to consult, some of which is listed in the "Additional Resources" section at the end of this guide. Rather, this guide provides suggestions from experienced CBPR practitioners in the field. For the purpose of this guide, all suggestions that were shared with me were included and grouped into 5 sections (listed below). CBPR is a fluid and partnership-specific process; therefore, readers

might consider this guide as a starting point for learning about the field. Differences in how partnerships approach the CBPR process are context-specific, thus some of the suggestions that follow may be more applicable to some partnership than others.

To develop this guide, suggestions from 10 experienced and successful CBPR partnerships from across the U.S. were collected. Suggestions were drawn from both the academic and community partners in these partnerships. This particular group of partnerships was interested in using CBPR to understand and take action to address health disparities by considering the many social factors, such as transportation, job security, and access to health and education that affect the health of their communities. While the focus of their work demonstrates one approach to CBPR, the lessons learned from these partnerships are useful to any community leaders thinking about this method. In sharing the collected suggestions of experienced CBPR practitioners, my hope is to serve as a conduit for their powerful voices and stories.

This guide is based on the ideas and stories from ten CBPR partnerships and is divided into five sections: 1) review of basic "need to know" principles of CBPR;
2) suggestions for how to plan to participate in a CBPR partnership before ever beginning;
3) ideas for engaging community participants; 4) tips for working with academic partners, and 5) suggestions for working with government and policymakers. Quotes from community and academic partners are used to help illustrate examples of what CBPR actually looks like on the ground and provide insider information into the real challenges and solutions involved in community-academic partner research.

Practical Suggestions

The Basics

In this section, some of the basic principles of CBPR are summarized. Community partners are encouraged to review this section as they begin to think about this approach to addressing health. These suggestions – as well as all of the suggestions in this guide – are based on lessons learned from the10 experienced CBPR partnerships. The tips in this section provide an overview of CBPR values and are consistent with CBPR principles that are well described in the academic literature (Israel, et al., 1998). This section of the guide is aimed at community partners who have less experience with CBPR. More experienced CBPR partners may want to skip ahead to the next sections.

Readiness. Consider the readiness of a community to address the problems that they are experiencing. How prepared a community is to recognize and to take actions to address problems can be assessed by partners before developing interventions. See the work of Colorado State University's Tri-Ethnic Center for more information about community readiness: http://triethniccenter.colostate.edu/communityReadiness_home.htm

Priorities. The *project* is the priority of the partnerships, not *individual* interests. In other words, the needs of all of the partners – including the community at large – come before the needs of any one person in the partnership. For example, graduate students may be collecting data from the project as a requirement for their PhDs; however, thoughtful consideration as to how such data are collected is useful so that it does not distract from overall goals and needs that have been identified by the partnership.

Trust. The need for trusting and honest relationships between community and academic partners cannot be overemphasize. But building trust takes time. This may be especially true for

communities that have experienced exploitation and/or misuse by members of the scientific community. However, as one community partner mentioned, “you have to develop this trust element. You know that’s very important in a community-based partnership. If you don’t have any trust, [the partnership] is not going to happen”.

Respect. Each partner has a unique set of skills and expertise that they bring to the partnership. Regardless of what academic degrees a partner may hold, no one partner’s skills should be considered more valuable that another’s. Humility and equity are important and essential ingredients of successful partnerships, which may be especially true in partnerships that may be unequal with respect to power.

Compensation. Community partners deserve to be compensated for their time, just like academic partners. Ideally, this would include compensation for attending meetings, presentations, trainings and/or other activities that are related to the project.

Ownership. Many people believe that in CBPR, the community should own the data. Ideally, academic partners contact community partners before presenting or publishing findings so that community partners have time to provide input and make changes where needed. Additionally, having access to project data can be useful for community partners in making a case to legislators and/or other people who have decision-making power that affects their community.

Challenge. At times, academic partners discuss and write about academic concepts and theories that can be difficult to understand. However, community partners can play an important role in providing feedback throughout the research process. One community partner discussed the importance of being involved in research even given limitations in terms of formal education,

"I challenge myself all the time… I don't have a science degree; however, I read these 2 inch reports with the dictionary right there next to me and I submit comments".

Sustainability. One goal of CBPR is for communities to continue the work of the partnership independently, even when grant funding is no longer available. One way to improve sustainability of a project is to integrate the work of the partnership into programs and services that already exist in the community. For example, one partnership that was interested in the health and safety of workers at high-risk job sites (e.g. manufacturing and construction) described how such companies are required to train workers in these settings. The partnership was able to add additional resources to the training that were useful in improving the health and safety of the workers. In this example, the partnership was able to integrate their materials into a service that was required in the community, increasing the likelihood that it would continue to be used.

Planning: Getting Needs Met from the Start

In this section, tips that community leaders might consider before beginning a research partnership are shared. Taking time to establish a strong foundation for a project at the beginning is a way for all partners to advocate for their needs and what they want to get out of the project. Community partners might consider the following tips before agreeing to a new CBPR partnership.

Homework. Community partners can interview potential academic partners to decide if they are a good fit for their communities. Community partners might also consider meeting with other communities that the academics have worked with to get candid feedback about their experiences.

Direction. Communities have an important role in deciding what questions to address through research that directly involves them. When communities do not help decide what issues to consider, there is less likelihood that the research will address a need that is important to them. This can result in a waste of money, resources, and time. Consider this analogy from one community partner:

> If I come to your house and I tell you hey, I'm going to look at your plumbing to see how it works and how I could improve it. [The homeowner] is going to tell you, the thing about it is, I don't have any issue with the plumbing – I'm not complaining about that. However, I am complaining about the broken windows that I have. So it becomes a different day when folks say– well, I specialize in plumbing, and you can say that I don't need your expertise in plumbing or the field of work that you're in. What I do need to find is somebody who works in a field that can help me with the broken window.

Listening. Community partners can learn about what a community wants to study by holding a series of community meetings, conducting a survey, or facilitating listening circles or focus groups. As mentioned, asking community members what issues are important to them helps ensure that time and energy spent on the project will result in findings that are useful and meaningful to the community.

Procedures. Community partners are encouraged to set up the rules of the game ahead of time. Consider creating a memorandum of understanding (MoU) that spells out each partner's rights, roles and responsibilities to the partnership. This is also a good place to formally document financial agreements.

Leadership. Consider organizing the partnership in a way that allows for multiple leaders, or principle investigators (PIs). PIs are the people who direct and oversee research projects. This way, multiple voices can take part in leading the research process.

Power. Collaborations between academic and community partners can present a situation where power dynamics appear to be uneven, as academic partners may be seen as having more power than their community partners. It is important for partners to think about the role of power in their relationships and decide what steps might be taken so that all partners have an equal voice in the research process. As one community partner noted, community partners have the right to "be treated as equals".

Equity. Consider how many community and academic partners is ideal to work together on your team. It might be that having equal representation from the community and the university could help maintain a process that more equitably reflects different voices and opinions.

Timelines. CBPR projects can be messy and require a lot of flexibility in order to succeed. In addition, community and academic partners may work in environments that have very different notions of time and deadlines. Engage in a dialogue about project timelines *before* the project begins, as well as throughout the research process. After all, people's time demands and project priorities are always changing.

Express. Community partners are encouraged to be clear about the needs of the community up front. For example, is it important that the partnership address issues as they come up rather than sticking to a set agenda? Do there need to be policy implications from the work as a partnership? These requirements will be different for each community, so feel free to share your needs and expectations from the start.

Finances. Community partners are encouraged to stay informed about how budgets are made, even when the money comes from the academic partner. For example, who will receive

and manage project funds? Community partners may ask that funds be allocated for a community fiscal agent who can help to advocate for finical needs and explain complicated financial jargon.

Coordination. Community partners may want to ask that academic partners appoint one person from the academic team to coordinate messages and information from all of the academic partners. This may be especially important when partnering with a large team of academic partners. Rather than receiving phone and email messages from several partners, one key contact person can be designated to communicate information.

Engaging Community Members

In this section, tips for community partners working to engage and include their communities in CBPR are shared. As discussed previously, community partners act as important bridges between the communities that they represent and the academic partners and institutions with which they partner. At times, the beliefs and ideas of the community partner may differ from those of some community members (Spies et al., 1998). Therefore, community partners play a crucial role in advocating for the multiple voices and input of community members. This is a delicate role to balance, as community partners are responsible to community members and other members of the partnership. For this reason, tips in this section provide guidance for how to support and engage community members.

Participants. Community members who participate in CBPR studies are referred to as participants, not subjects.

Hiring. Community partners can suggest that members of the community are hired to work on the study rather than exclusively hiring students or professionals. As one community partner noted, "You cannot improve the infrastructure of a community without improving their lives. You know, by hiring people [from the community] and teaching them". In addition,

community members may be better at communicating the importance of the project to other members of their community, especially when language differences between project partners and community members exist.

Clarity. When recruiting community participants, it is important that community partners communicate the main ideas of the project in language that is clear and direct. Technical or scientific terms may have little meaning to community members. In addition, words may have different meanings across languages. For example, in Spanish, participating in a *program* is understood to have a long-term commitment whereas participating in a *project* is understood to have a specific end date. Being clear about what the project looks like, and what the timelines will be, can help community members to decide if they are able and willing to participate.

Flexibility. Project procedures can allow for flexibility. For example, the initial plan might be that community participants meet every month to participate in an activity. It may turn out that participation drops when meetings are spread too far apart. Community partners might consider ways to adjust timelines. For this example, community partners could try having participants meet every week or every other week to keep them interested and involved.

Materials. Materials for the project, such as surveys, flyers and information sheets can be created by both academic and community partners to make sure they are culturally appropriate and useful for the community. Community partners can help evaluate participants' responses to the materials and can make changes if needed.

Translation. When doing a survey with community members, it is important to keep in mind that typical survey questions in the U.S. do not always translate well into different languages or cultures. For example, in the U.S., a standard depression survey question asks respondents to rate how often they "feel blue". The concept of "feeling blue" is not understood

by everyone. As such, questions are often reworded in order to make sense to community participants. Still, there might be times when academic partners want to use questions that have been used in previous studies. This can be useful particularly if communities want to compare their findings to the findings of other communities. Therefore, it is important that community partners work closely with academic partners to be certain that the translation of survey questions is accurate and will make sense to community members.

Communication. Community partners can help keep community members informed about the work that partnerships are doing by creating a newsletter or speaking on a local radio or television show. Information about the partnership can also be shared with a variety of community leaders, such as religious leaders, local aldermen and women and school district superintendents. These individuals may be representing hundreds – or even thousands – of people and can help get the word out.

Diversity. There is considerable diversity within racial and ethnic communities. For example, Latinos can be from Spain, Central and South America, the Caribbean, etc. As a result, the way that messages are communicated to different segments of the community is important. The way partnerships conduct outreach should also be tailored to connect with the specific demographics of the community.

Note cards. When holding a meeting with a large group of community participants, community partners might consider handing out note cards to everyone in attendance so that participants can write down questions that come up. The note cards can then be collected toward the end of the meeting and addressed immediately or at a later meeting. This way, the first voice to speak will not be the only one that is heard, and it also gives people more time to think.

Probing. Community partners can help engage communities in thinking about the problems behind the problems. For example, if crime rates are higher in one neighborhood than the one right next to it, community participants can discuss why they think that is. Is the solution something as simple as installing additional street lighting, or are there deeper structural issues at play? Another example would be if community members start to see a lot of garbage in front of their neighbors' homes, is this because neighbors are littering, or are they being evicted without a place to move their belongings?

Organizing. Community partners might consider building in a community organizing component to CBPR projects. Doing so can help communities network, create tactics to address problems, and increase power.

Data. Gathering a variety of types of data, such as stories, pictures, maps, and statistics, can be useful in helping to demonstrate a problem and understand why it exists. Community partners can use available data to illustrate demographics of the community. Census data are free and readily accessible online at http://www.census.gov/. Data may also be available from U.S. consulates, public health departments, school districts, and other organizations. It is important to know the audience and what kind of data they value. When talking with policymakers, for example, facts and statistics might be useful in understanding and addressing the needs of the community, along with stories.

Stories. Community stories are an important form of data collection. Community partners can help to facilitate the gathering of these data when they are available to listen and to learn. Sometimes stories are better than statistics at describing the complexity of an issue. Stories can be used to put a human face on a problem, which can be useful to elected officials. Voice

recorders or cameras can be useful tools to capture stories and images, especially if literacy is an issue.

Presentation. When the project's findings are shared with community participants, as well as the community at large, they can be asked how they would like to see the data presented, e.g. in the form of a pie chart, line graph, bar graph, pictogram, etc. Community partners may also want to share examples or case studies that assist community participants in practicing how to read and interpret findings.

Reciprocity. If there are plans to survey community participants, community partners might consider ways not only to gather information, but also to offer resources that are easily accessible and useful. For example, community partners can provide a list of classes at the local community center, educational opportunities and other helpful services.

Benefit. Community participants often receive some kind of benefit for time dedicated to the project, whether it is education, financial reimbursement for their time, or some other form of compensation.

Evaluate. Community partners can help to create a way to evaluate whether or not the project is making a positive impact in the community. For example, community feedback can be collected by holding focus groups or talking circles where community participants can share their feedback and hear each other's ideas.

Working with Academic Partners

In this section, tips for community partners that may be helpful in thinking about how to navigate issues that may come up in their relationships with their academic partners are shared. Often community and academic partners work and operate on very different schedules, and, potentially, have different priorities. In addition, barriers such as geography can be difficult,

especially when partners live in different locations. In this section, tips for how community partners can negotiate relationships with academic partners are provided.

Resources. Partnering with universities often increases access to skills, resources, and the ability to disseminate findings from partnerships. Communities are often in a constant state of "putting out fires", in other words, addressing more immediate needs. Partnering with universities can help communities to explore problems in a more comprehensive way and can explore more long-term goals and outcomes.

Introductions. Face-to-face introductions between members of the partnership can be helpful, especially if a lot of communicating will be done over the phone. It is easy to get confused about who is talking on conference calls when partners have never met.

Discuss. When partners meet to discuss the project, they can consider starting the meeting by having all of the academic partners sit together in one group and all of the community partners sit in another. In these groups, the partners can talk about any concerns or tensions that have come up since the last meeting. The groups can then get together and communicate their concerns on behalf of the group rather than on behalf of an individual. This offers individual partners the ability to voice concerns that might be difficult to bring up alone.

Facilitate. Community partners can advocate for having a social worker, an external evaluator, or some other objective individual included in the partnership who can help facilitate communication between partners.

Participation. It is common for projects to have regular meetings with all members of the partnership. However, not all parts of the meetings may be useful or meaningful to community partners, for example, complex discussions of mathematical formulas or theories among academic partners. It is legitimate for community partners to ask that they only

participate in the parts of the meetings that directly involve them in the conversation. Community partners may propose to set an agenda where all of the items that are of concern to them are at the beginning of the meeting, after which time they can leave. That said, community partners have the right to be involved in all parts of the meetings if they are interested in learning more about what the academics are planning in relationship to the project.

Accountability. Community partners are encouraged to hold their academic partners accountable for requirements they need to fulfill for funding purposes. For example, if academic partners have the primary responsibility for publishing results from the study as a requirement of the partnership receiving funds, community partners can check with them to see where they are at with publishing results.

Publications. Academic partners often need to publish findings from their work as part of their professional responsibilities. Doing so can be useful in disseminating important results from the partnership, as well as increasing recognition of the work. However, community partners can be clear with academic partners that publications – and publication timelines – are not the only priority of the partnership. In addition, the needs and opinions of community partners are important to be consider when writing articles. As one community partner shared,

> Academics really need to write articles. Academics really need to present at conferences, and there is a reciprocal understanding in terms of when the academics would say, we would really like to write an article on this, and we'd really like your input.

In addition, when publications do result from your partnerships, advocate for appropriate recognition. For example, community partners are often listed as co-authors on CBPR publications.

Students. Community partners can assist in recruiting students from a variety of degree programs, including public health, urban and regional planning, law, social work, medicine, etc. A core of student volunteers can support a sustainable infrastructure that can be helpful, especially when funding is limited. However, it is important that students are well oriented to the project and the community before beginning.

Celebrate. Community partners can suggest organizing an annual party or retreat where all partners on the project can celebrate each other and reflect on the project. This is also a great time to reflect on the past year and to set goals for the future.

Involving Government and Policymakers

In this section, tips for community partners who are interested in engaging governmental agencies and policymakers in the work of their partnerships are shared. Such individuals and organizations often have a great deal of power in terms of how funding is distributed, as well as how policies are created and carried out, in communities. These tips can help community partners to start thinking about how to involve critical stakeholders throughout the research process.

Stakeholders. Think about adding partners from multiple organizations, such as public health departments, city or regional planning and transportation departments and other governmental and non-governmental programs that directly address the issues that are relevant to the community. Such partners carry weight in terms of influencing government and policymakers. It is important to always be thinking about who is not in the room that needs to be there. Even within one community, dozens of smaller communities exist based on such characteristics as gender, socioeconomic status, race and culture. Therefore, bringing together a

diverse group of community partners can help to represent the community in a more complete way.

Visual. Community partners might consider inviting local policymakers into the community so they can see first-hand the conditions that require their attention. For example, if several houses in the city are boarded up and pose a safety concern, those can be pointed out.

Summary and Final Thoughts

The time to address the health of racial and ethnic community in the U.S. is *now*. CBPR is one approach that is useful in tackling health disparities. The information gathered from 10 successful CBPR partnerships and summarized here provides a guide for community partners interested in partnering with academic researchers to address health. In closing, here are a few quotes from community partners that hopefully inspire and encourage community partners to consider this sometimes challenging, but very exciting and useful, approach!

> *~ Let's say you were steering, steering a ship. The direction and the things – and how a decision would be in terms of navigating forward – [that] would be the community group. And then the academics being like a real resource to empowering that community group. And then providing the tools and the resources to help navigate the ship through.*

> *~ The community is waking up to the day where researchers cannot impose themselves to the community because they want get their doctorate degree or they want to bring in more money for their institutions. Communities now, in my view, are demanding that they get respected.*

> *~ All you have to have is the determination and hope to have a voice and you know it's better. You know, I think in the long-run, it might be a long struggle; however, I feel that the betterment of mankind will overcome.*

Additional Resources

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DISCUSSION AND IMPLICATIONS

Health disparities disproportionately affect racial and ethnic minorities U.S. and are large and persistent over time (Syme, 2008; Williams & Mohammed, 2009). This persistence occurs in part because health disparities are produced by a complex combination of broad SDH, such as poverty, low education, stress, employment status, access to health care, and neighborhood conditions (Dressler, 2004; Li & Robert, 2008; Mays, et al., 2002; Niederdeppe, et al., 2008; Robert & Booske, 2009; Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; Williams & Jackson, 2005; World Health Organization: Commission on Social Determinants of Health, 2008). These SDH shape individual-level health behaviors and practices that are more proximal determinants of health. Moreover, these SDH also affect health more directly to create and maintain health disparities (Israel, et al., 2010). Thus, solutions to this continuing and growing problem of health disparities should address the variety of social factors that contributes to differences in health across groups. In the U.S., we have yet to find approaches that are consistently successful at significantly reducing health disparities.

CBPR is one method that is well-documented in engaging communities in research that addresses their health (Israel, et al., 2001; Israel, et al., 1998; Potvin, et al., 2003; Rios, et al., 2008). CBPR is characterized by partnerships between community leaders and academic researchers and ideally fosters empowerment, equity, respect, and shared responsibility among all members of the research team. In theory, such partnerships help to identify and address the complex factors that are affecting health in the community by bringing many people together with varied expertise and commitment to improvement. However, rather than considering the larger social conditions that foster health disparities, as well as multilevel solutions needed to mitigate these complex social problems, many CBPR studies focus primarily on changing public

attitudes and opinions around specific topics (Beck, et al., 2007) or changing individual health behaviors. Such limited approaches risk "victim blaming", as well as overlooking the root causes of health disparities (Israel, et al., 1994; Kannan, et al., 2009).

This dissertation was designed to identify some of the CBPR projects in the U.S. that have been successful at identifying and addressing the SDH in their projects, in order to learn from their accomplishments. In addition, this study sought not only to examine how these partnerships were successful at achieving *outcomes* that addressed the SDH but also the degree to which they created a research *process* that was empowering for the entire research team. The goal of this research project is to provide knowledge to maximize the ability of future CBPR projects to create both a process that is empowering to all participants in the partnership, and outcomes that will more holistically address the broad SDH that create and maintain health disparities.

Summary of Key Findings

Findings from this study answered four research questions:

Q1. What is the process by which SDH emerge, by whom and at what point in the research process?

Q2. What are factors that promote investigating and addressing the SDH in CBPR projects?

Q3. What are the factors that inhibit investigating and addressing the SDH in CBPR projects?

Q4. How do perceptions about the process of investigating and addressing the SDH within a CBPR project compare between academic and community partner dyads who work together on the same project?

Regarding Question 1, findings suggest that in partnerships where shared influence, control and respect were present (which was true of the overwhelming majority of partnerships

included in this study), SDH that were of importance to the partnering community emerged over time and were understood to be important by community and academic partners, as well as the community at-large. These SDH were generally identified before a study began; however, several partnerships discussed a willingness to address new SDH that affected the partnering community as they developed.

Regarding Question 2, findings suggest that there are several factors, including political support and partnership characteristics such as an overt shared commitment to investigating and addressing the SDH by the partners and a long-term relationship as a partnership, which promote investigating and addressing the SDH throughout a CBPR process.

Regarding Question 3, findings suggest that factors that inhibit investigating and addressing the SDH in CBPR processes include historical circumstances, low socioeconomic status of the partnering community and the political climate.

Regarding Question 4, findings suggest that the overwhelming majority of partnerships included in this study indicated that within their academic-community partner dyads, there were similar perceptions of the research process. In other words, partners were generally consistent in describing the process by which SDH were selected to study, by whom and at what point in the research process.

In addition to addressing these four research questions, a set of suggestions for community partners interested in participating in CBPR partnership was developed based on the practical suggestions and tips from the experienced partnerships included in this study.

Findings across studies. Looking across the three papers**,** one of the main findings of this study is that in many instances, partners that shared long-term relationships as a partnership (a facilitating factor, Q2) shared benefits that have meaning for several of the research questions.

For example, those partners that had long-term relationships as a partnership were more likely to share an understanding of which SDH were important to address in research (Q1). They were also more likely to have similar perceptions of the research process (Q4) and share feelings of empowerment as it related to participating in the research process (Q4). Over time, partners also indicated that trust and respect increased, which they described as important principles of CBPR practice.

It is not surprising that a long-term commitment to addressing the SDH would be beneficial. Partnerships dedicated to investigating and addressing these complex factors confront a host of challenges such as work in dynamic settings; loss of motivation; needed attention to other projects or commitments; or any number of other interruptions that inhibit progress (Wallerstein & Duran, 2006). Thus, partnerships that endure over time while contending with unforeseen barriers may be the exception rather than the rule.

However, it should be noted that this study did not identify length of time that partnerships had been together as a *causal* factor with regard to their success in investigating and addressing the SDH. Rather, length of time as a partnership appears to be an important correlate that warrants additional study as it relates to investigating and addressing these factors. Future studies might look at CBPR partnerships that have been together for different lengths of time to see how the projects unfold over time, when SDH are able to be fruitfully addressed, and what factors contribute to building and maintaining partnerships long enough to reap the most success in identifying and addressing the SDH.

In addition, length of time as a partnership may be connected with an increased capacity to achieve desired *goals and outcomes* but does not necessarily imply that the *process* by which results were achieved was equitable and empowering. Indeed, a partnership could feasibly be

maintained for years without fostering an equitable research process. Thus, future research is needed in order to determine how to foster a meaningful and empowering research process throughout the duration of CBPR projects. Such a process may actually lead to CBPR projects lasting longer so that partners can adequately address the SDH will also attending to the needs and preferences of all partners.

Limitations

One limitation of this study is that only partnerships that overtly investigated and addressed the SDH were invited to participate, which disallows a comparison of partnerships that do not investigate and address the SDH. However, for this exploratory study in which little has been reported about the intersection between SDH and CBPR, the main focus was to gather information about those CBPR partnerships that *do* investigate and address the SDH.

Additionally, not all members of the ten CBPR partnerships were interviewed. In some cases, the actual partnerships consisted of a dozen or more partners. However, I generally interviewed only one academic and one community partner per project with a focus on those partners who were intricately involved in investigating and addressing the SDH. Speaking with a larger number of partners from each CBPR partnership may have demonstrated greater differences in perceived level of empowerment within the partnerships, as well as different beliefs around factors that facilitate and inhibit investigating and addressing the SDH.

Moreover, partners were only interviewed one time. While a thorough review of published articles, grant reports, white papers, community reports, and conference presentations was conducted before interviewing each participant – providing extensive information about the histories and details of each partnership – concerns due to partner recall of details of a project may have resulted in inaccurate data.

Finally, conducting a truly exhaustive search of CBPR studies that investigate and address the SDH proved difficult, as the broad nature of SDH means that many diverse disciplines incorporate this framework, whether they refer to it specially or not. For this reason, snowball sampling methods proved valuable in identifying studies across disciplines that might otherwise have been difficult to locate. Moreover, issues of memory bias, which can alter recall of events, people, place etc., may have influenced the content of partners' responses.

Advancing Scholarship

Despite noted limitations, the fields of CBPR and social work appear well situated to investigate and address SDH. Social work is a highly applied social science in which the aim of research is to produce knowledge that can be used to improve the lives of underserved communities. By being involved in a community-based approach to research that integrates and addresses the SDH, social workers might better understand the complex set of factors that influence health and health disparities through their partnerships with communities. Doing so will require additional research to determine an appropriate balanced with regard to meeting immediate needs of communities with more long-term solutions to health disparities that critically investigate and address the SDH. Hopefully the lessons learned from this study will assist social workers as they participate in CBPR projects as academic partners, community partners, or consultants/facilitators.

Given our rich understanding of the complex factors that influence communities, social workers can play a critical role in advancing the field of CBPR so that *all* studies that use this approach at least consider how and why SDH play a role in creating and maintaining health disparities. This proposition is not meant to discredit a rich history of accomplishments experienced by CBPR practitioners; rather, it is a bold call to action. Despite years of research

and investigation, differences in health across racial and ethnic groups persist, in part because we have yet to thoroughly investigate and address the root social, economic and political conditions that give rise to and perpetuate these disparities. Given our increasing understanding of how the SDH influence wellbeing (Robert Wood Johnson Foundation Commission to Build a Healthier America, 2009; World Health Organization: Commission on Social Determinants of Health, 2008), it is time that the field of social work, as well as CBPR practitioners, respond by taking steps to consider how the SDH influence our understanding of health disparities and, eventually, move towards investigating and addressing SDH in all partnerships.

Moreover, the profession of social work is guided by the principle of empowerment, the process whereby individuals and groups gain confidence to voice opinions, make choices and garner power and control over issues affecting their lives (Titterton & Smart, 2008; Tsey, 2009). Findings from this study suggest the importance of understanding whether or not all partners in a CBPR project perceive the research process to be empowering. Even CBPR projects that are successful in terms of accomplishing their goals can be lacking in terms of maintaining a process that is positively perceived by all partners. Thus, further research is needed to determine whether or not greater feelings of empowerment by all members of a CBPR partnership may actually improve outcomes with respect to project goals. Social workers can help insure that a CBPR process is empowering for both academic and community partners, contributing to both CBPR processes and outcomes that are more likely to promote wellbeing and reduce disparities.

APPENDIX A

CONTACT INFORMATION FORM

Thank you for your interest in this study. The purpose is to learn how community and academic partnerships work together to reduce health disparities. If you are willing to participate in this study, you can contact the study's director by phone at 847.975.8498 or by email at rrparadiso@wisc.edu. If you would rather have the study's direct contact you, please complete this form and email it to rrparadiso@wisc.edu or mail a copy to the address below:

Rebecca Paradiso de Sayu, PhD candidate
Waisman Center - Room 527
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705

Name(s) _____Date_____

Phone Number_____ (during the day)

_____ (during the evening)

Best hour to reach me _____ (AM/PM)

Email Address_____

Do you prefer to be contacted by phone or email? _____

Thank you!

APPENDIX B

SURVEY TOOLS

The Process of Addressing the Social Determinants of Health in Community-based Health Research: Academic Partners

Thank you for agreeing to talk to me today about (**insert name of specific project**). As you know, there are many factors, or *social determinants of health*, that affect health. Social determinants of health are "the conditions in which people are born, grow, live, work and age, including the health system" During this interview, I am going to ask you questions about how your work has looked at social factors, like ***(XY social factors)***, to address health disparities. Do you have any questions before we begin?

1. I would like to learn more about the background of (**insert name of specific project**).

1a. Could you please tell me more about the story of this **partnership** from when it first began?

1b. What was the series of events that led the (**insert name of specific project**) to where it is today?

1c. How was the **project** developed?

Prompt: What were the steps in deciding what to research?

Prompt: Who were the key players and leaders in this project? Please provide names and the roles each person played in the project.

2. In your project, you look at how ***(XY social factors)*** affect health.

2a. How was it decided to focus on these factors?

2b. Can you please describe the point in the research process when academic and community partners decided to address (**XY social factors**)?

2c. Can you please tell me more about who raised the issue of addressing (**XY social factors**)?

3. In general, how important do you feel ***(XY social factors)*** are to the health of your partnering community?

3a. How did academic and community partners decide that these factors were meaningful to the partnering community?

3b. Were these factors of great concern to your partnering community before working on this project? Can you please say more?

3c. Were there other social factors that were of concern to **your partnering community** that were not studied in this project?

3c1. **If Yes**: Why were those factors not studied in this project?

3d. Were there other social factors that were of concern **to you** that your partnering community decided not to study?

3d1. **If Yes**: Why were those factors not studied in this project?

4. I am interested in learning more about how your partnership was able to study ***(XY social factors)*** in the project.

4a. What conditions do you believe helped to address ***(XY social factors)*** throughout the research process?

Prompt: Please provide examples from your research.

5. What conditions do you believe made it difficult to address ***(XY social factors)*** throughout in the research process?

Prompt: Please provide examples from your research.

6. Now I would like to ask you some questions about how you and your community partners felt throughout the research process.

6a. Were your ideas valued and respected throughout the research process?

6a1. **If Yes:** What are some of the ways (if any) that your community partners showed you that you were valued and respected?

6a2. **If No**: Can you please say more about why you feel your community partners failed to show you that you were valued and respected?

6b. Were the ideas of your community partners valued and respected throughout this project?

6b1. **If Yes:** What are some of the ways (if any) that you showed your community partners that they were valued and respected?

6b2. **If No**: Can you please say more about why you feel your community partners were not valued and respected?

7. What suggestions do you have for other academic scholars interested working on community-based health projects that study social factors such as ***(XY social factors)***?

8. Is there anything else you would like to share?

Thank you so much for your willingness to participate in this interview, I truly appreciate it. If I have follow-up questions or clarification in regard to this interview, would it be okay for me to contact you again?

The Process of Addressing the Social Determinants of Health in Community-based Health Research: Community Partners

Thank you for agreeing to talk to me today about (**insert name of specific project**). As you know, there are many factors, or *social determinants of health*, that affect health. Social determinants of health are "the conditions in which people are born, grow, live, work and age, including the health system" During this interview, I am going to ask you questions about how your work has looked at social factors, like ***(XY social factors)***, to address health disparities. Do you have any questions before we begin?

1. I would like to learn more about the background of (**insert name of specific project**).

1a. Could you please tell me more about the story of this **partnership** from when it first began?

1b. What was the series of events that led the (**insert name of specific project**) **to** where it is today?

1c. How was the **project** developed?

Prompt: What were the steps in deciding what to research?

Prompt: Who were the key players and leaders in this project? Please provide names and the roles each person played in the project.

2. In your project, you look at how ***(XY social factors)*** affect health.

2a. How was it decided to focus on these factors?

2b. Can you please describe the point in the research process when academic and community partners decided to address (**XY social factors**)?

2c. Can you please tell me more about who raised the issue of addressing (**XY social factors**)?

3. In general, how important do you feel ***(XY social factors)*** are to the health of your community?

3a. How did academic and community partners decide that these factors were meaningful to your community?

3b. Were these factors of great concern to your community before working on this project? Can you please say more?

3c. Were there other social factors that were of concern to **your academic partner** that were not studied in this project?
3c1. **If Yes**: Why were those factors not studied in this project?

3d. Were there other social factors that were of concern **to you** that your academic partner decided not to study?

3d1. **If Yes**: Why were those factors not studied in this project?

4. I am interested in learning more about how your partnership was able to study ***(XY social factors)*** in the project.

4a. What conditions do you believe helped to address ***(XY social factors)*** throughout the research process?

Prompt: Please provide examples from your research.

5. What conditions do you believe made it difficult to address ***(XY social factors)*** throughout in the research process?

Prompt: Please provide examples from your research.

6. Now I would like to ask you some questions about how you and your academic partners felt throughout the research process.

6a. Were your ideas valued and respected throughout the research process?

6a1. **If Yes:** What are some of the ways (if any) that your academic partners showed you that you were valued and respected?

6a2. **If No**: Can you please say more about why you feel your academic partners failed show you that you were valued and respected?

6b. Were the ideas of your academic partners valued and respected throughout this project?

6b1. **If Yes:** What are some of the ways (if any) that you showed your academic partners that they were valued and respected?

6b2. **If No**: Can you please say more about why you feel your academic partners were not valued and respected?

7. What suggestions do you have for other community members interested working on community-based health projects that study social factors such as ***(XY social factors)***?

8. Is there anything else you would like to share?

Thank you so much for your willingness to participate in this interview, I truly appreciate it. If I have follow-up questions or clarification in regard to this interview, would it be okay for me to contact you again.

APPENDIX C

INFORMED CONSENT FORM

UNIVERSITY OF WISCONSIN-MADISON
Research Participant Information and Consent Form

Title of the Study: How Community Based Participatory Research Partnerships Investigate the Social Determinants of Health in Low-Income Racially and Ethnically Diverse Communities in the United States

Principal Investigator: Stephanie Robert (phone: 608.263.6336, email: sarobert@wisc.edu)

Student Researcher: Rebecca Paradiso de Sayu (phone: 847.975.8498, email: rrparadiso@wisc.edu)

DESCRIPTION OF THE RESEARCH

You are invited to participate in a research study about how community based participatory research (CBPR) has been used to research social factors that affect health. The purpose of the study is to learn about how community and academic partnerships work together to address social factors that influence health. You have been asked to participate because you have participated in a CBPR project that addresses social factors that affect health.

This study will include a sample of at least ten academic and community partnerships that have worked together to address social factors that influence health. Interviews will be conducted over the telephone or Skype. Digital recordings will be made of your participation. A digital recorder with a microphone attached to the telephone receiver or computer speakers will be used to capture data accurately and will be used to analyze themes discussed in the interviews. Transcripts of the digital recordings will be professionally transcribed and stored in a locked filing cabinet. Only the research team will have access to the printed transcripts and audio recordings. Digital recordings and transcripts of the interviews will be kept for no more than five years before they are destroyed.

WHAT WILL MY PARTICIPATION INVOLVE?

If you decide to participate in this research you will be asked to participate in an approximately 1hour telephone or Skype interview in which you discuss your experience working on a CBPR project that studies the ways in which social factors influence health.

ARE THERE ANY RISKS TO ME?

We do not anticipate any physical, social, economic or legal risks to you from participation in this study. However, if there are questions in the telephone or Skype interview that make you uncomfortable, you are free to skip these items without needing to provide reasons for doing so.

ARE THERE ANY BENEFITS TO ME?

We do not expect any direct benefits to you from participation in this study; however, the information gathered in this study may help to advance the field of community-based research such that social factors are considered in studies that address the health of your community and communities throughout the United States.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

If you agree to participate in this study, a $400 donation to the American Cancer Society will be made in honor of your time and dedication to the project.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

While there will likely be publications as a result of this study, your name will not be used. Only group characteristics will be published. If you participate in this study, we would like to be able to quote you directly without using your name. If you agree to allow us to quote you in publications, without using your name, please initial the statement at the bottom of this form.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask any questions about the research at any time. If you have questions about the research after you leave today you should contact the student researcher, Rebecca Paradiso, PhD candidate at 847.975.8498. You may also call the Principal Investigator, Stephanie Robert, PhD at 608.263.6336. If you are not satisfied with the response of the research team, have more questions, or want to talk with someone about your rights as a research participant, you should contact the Education Research and Social & Behavioral Science IRB Office at 608-263-2320.

Your participation is completely voluntary. If you decide not to participate or to withdraw from the study it will have no effect on any services or treatment you are currently receiving.

Your signature indicates that you have read this consent form, had an opportunity to ask any questions about your participation in this research and voluntarily consent to participate. You will receive a copy of this form for your records.

Name of Participant (please print):_____

_____ _____

Signature Date

_____ I give my permission to be quoted directly in publications without using my name.

Initials

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