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Faculty perspectives on community-based research: "I see this still as a journey"

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Abstract

Academic faculty members are increasingly following community-based participatory research (CBPR) principles. We conducted qualitative, in-depth interviews with 22 Johns Hopkins faculty members who conduct community-based research to understand their experiences and perspectives. Respondents engaged the community in numerous ways, ranging from working with community advisory boards to hiring community members as project staff to collaborating with community members across all phases of research. Challenges included defining "community," ensuring adequate community representation, sharing power with community partners, overcoming an institutional history of strained community-academic relationships, and working within existing academic incentive structures. Despite these challenges, respondents generally felt their experiences conducting research with community participation were positive and successful. Policy changes at funding and academic institutions and an emphasis on the similarities between CBPR and ethical principles could improve support for CBPR approaches.

Keywords

ethics of community-based participatory research; community-academic partnerships; qualitative research; in-depth interviews; faculty; academic medicine

Academic institutions increasingly have been called upon to act as good citizens and serve their communities through research and other core activities (Astin, 1999; Boyer, 1990; Nyden, 2003). Community members, researchers, and funding agencies have recognized the rights of communities to be participants in, not merely subjects of, the research that concerns them, and above all to benefit from this research (Emmanuel et al., 2004; Green & Mercer, 2001; O'Fallon & Dearry, 2002; Higgins & Metzler, 2001). There is also a growing desire among many faculty members to conduct research that has direct benefits for participating

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communities, and to use research as a vehicle to reduce social injustices such as harmful environmental exposures and health disparities (Nyden, 2003; Minkler & Wallerstein, 2003; O'Fallon & Dearry, 2002; Viswanathan et al., 2004).

The community-based participatory research (CBPR) approach has been proposed as a means of achieving these goals. CBPR aims to understand communities' health priorities, to design research that addresses these priorities, and to involve communities throughout the research process (Israel et al., 1998). CBPR is guided by core principles—summarized in a seminal review article by Israel et al. (1998)—which distinguish the approach from community-based research that does not involve active community partnership.

Proponents of CBPR emphasize its unique contributions to the research process and its potential to enhance community well-being. The local knowledge and expertise that community partners contribute may improve the quality and validity of research and generate research findings that have more direct relevance to participating communities (Israel et al., 1998). Participation in research may also increase a community's capacity to address its health priorities (Wallerstein & Duran, 2003; De Koning & Martin, 1996). Finally, the CBPR approach may empower communities to advocate for program and policy changes indicated by the research findings (Israel et al., 1998; Wallerstein & Duran, 2003; Vasquez, Minkler, & Shepard, 2005; Lee, Krause, & Goetchius, 2003). Along with these benefits, however, the CBPR approach introduces new challenges into the research process. CBPR practitioners grapple with how to create equitable partnerships within conditions of social inequality (Israel et al., 1998; Wallerstein & Duran, 2006), how to succeed in academic settings that do not directly reward faculty involvement in community-based research (Nyden, 2003; Israel et al., 1998; Ahmed et al., 2004), and how to produce benefits for participating communities when project funds are insufficient for direct compensation or service provision (Israel et al., 2005; Parker et al., 2003).

A large body of literature offers guidance on how to navigate these and other challenges encountered when following the CBPR approach. Many of these articles are conceptual in nature, proposing key principles for CBPR, describing factors that may facilitate the partnership process, and offering strategies for addressing challenges (Israel et al., 1998; O'Fallon & Dearry, 2002; Israel et al., 2003; Community-Campus Partnerships for Health, 1999; Minkler, 2005; Bringle, Games, & Malloy, 1999; Seifer, 2003; Israel et al., 2001; Green, 2003; Minkler et al., 2003). Others present case studies of CBPR projects and offer lessons learned (Parker et al., 2003; Lantz et al., 2001; Eisinger & Senturia, 2001; Freudenberg, 2001). A smaller number of articles provide a comparative perspective across multiple CBPR projects (Metzler et al., 2003; Israel et al., 2006; Seifer & Calleson, 2004). Of these, to our knowledge, only one empirical article has used qualitative research methods to explore respondents' perspectives in-depth across a broad sample of community-based research projects (Sullivan et al., 2001). The majority of data presented, however, were from project staff and community partners, leaving the experiences of faculty collaborators largely unknown.

This study aimed to learn about faculty perspectives on the CBPR approach, and to explore the various ways faculty are implementing this approach in the field. To achieve these aims, we conducted qualitative, in-depth interviews with faculty members at one major academic health institution who were working on a variety of community-based research projects.

Method

Setting

This study was conducted by the Environmental Justice Partnership (EJP), a community-academic partnership located in Baltimore, Maryland, USA. The EJP partners include: (1) a community board composed of residents, advocates, and representatives from community-based organizations located in the East Baltimore neighborhood, (2) Johns Hopkins Bloomberg School of Public Health (JHSPH) faculty and staff, and (3) Maryland Institute College of Art graphic design faculty. The main goal of the EJP is to develop equitable and sustainable partnerships between researchers and local communities by promoting long-term dialogue and facilitating the translation of research into usable applications for community benefit.

To better understand local experiences with community-academic research partnerships in its particular setting and institution, the EJP conducted three studies exploring the perspectives of both community members from East Baltimore and researchers from the Johns Hopkins Medical Institutions (JHMI) related to community-based research. The first study consisted of interviews and focus groups with East Baltimore community members (Goldberg-Freeman et al., 2007), while the second study involved a quantitative survey of JHMI faculty and staff (Farfel, Goldberg-Freeman, & Vogel, 2005). The third study is reported here.

East Baltimore, home to JHMI, is a predominantly African-American (98%) urban community with especially poor population health and neighborhood conditions (Baltimore City Health Department, 2000). Residents are affected disproportionately by numerous health conditions including stroke, diabetes, cancer, HIV, sexually transmitted infections, violence, and substance abuse (Fox et al., 2004). The community has high rates of unemployment (13%), poverty (84% of residents have an annual income under \$20,000), and dilapidated housing (Gomez & Muntaner, 2005; Farfel et al., 2003). In addition, the neighborhood is the site of a major urban redevelopment project, which has led to significant residential demolition and displacement (Farfel et al., 2003; Cohen, 2007). In response to these and other challenges, community organizations and community leaders, many of whom are members of the EJP, are working to improve quality of life in the neighborhood.

Sampling Strategy

Our aim in this study was to capture a broad spectrum of faculty experiences with community-based research. We wanted to include an array of individuals, from those consciously following the CBPR approach to those who conduct research in community settings but do not identify themselves as CBPR practitioners. To achieve this aim, our eligibility criteria were being a JHMI faculty member and ever having conducted community-based research in Baltimore. Respondents were recruited through a combination of three sampling strategies: self-referrals, purposeful sampling, and snowball sampling. In the quantitative survey of faculty and staff, we included the self-referral question, "If your research has ever involved collaboration with East Baltimore leaders or community organizations, would you be interested in participating in a one-hour in-person interview as part of this study?" We also extended invitations to researchers we knew to be involved in community-based research in Baltimore. We purposefully selected researchers from all three JHMI schools (Public Health, Medicine, and Nursing), as well as tenured and non-tenured faculty, men and women, and faculty from a variety of racial and ethnic backgrounds, in order to capture as much diversity as possible in experiences and perspectives. Finally, at the end of each interview, we asked respondents for recommendations of other faculty members to interview.

Data Collection

The semi-structured, in-depth interview guide (see Appendix I) was developed collaboratively by members of the EJP. Two of the authors (AV and CGF) conducted one-on-one interviews with respondents. Most interviews lasted about an hour, although a few lasted longer. All respondents provided informed consent and agreed to have their interviews tape-recorded. Respondents received a \$10 gift card for the JHMI coffee shop. The JHSPH Institutional Review Board approved this study.

Data Analysis

We used thematic coding and memo-writing to analyze interview data (Morse & Richards, 2002). All interviews were transcribed, and codes were developed to identify the major themes that emerged. The two interviewers (AV and CGF) read all of the transcripts and worked collaboratively to develop a codebook that benefited from both of their perspectives on the data. These codes were then revised by a third author (CK), based on her reading of the transcripts, to develop a final codebook. Final codes were applied to all transcripts, and the coded text was read to identify additional themes and insights. Short memos were created to summarize the main themes in each interview. Finally, coded text was reviewed in its original context to ensure the validity of the analysis. We used Atlas.ti qualitative data management software (version 5.2, Scientific Software Development GmbH, Eden Prairie, MN) to facilitate coding and analysis.

Once most interviews had been coded, we sought member validation of our preliminary findings. Following CBPR principles, we presented our preliminary results to interview respondents and engaged them in a discussion about the data (Bloor, 1988). Respondents who were unable to attend the presentation were asked to provide comments by e-mail on the presentation slides. About a third of respondents provided some form of feedback. We also presented preliminary results to the EJP board, in order to receive a community perspective on our preliminary findings. Feedback from interview respondents and EJP board members informed our analysis.

Results

Sample Characteristics

Our sample included 22 respondents, of whom 7 were self-referred from the faculty survey, 11 were identified through purposeful sampling, and 4 were recruited through snowball sampling. As expected based on our sampling methods, these respondents were quite diverse (Table 1). Respondents described dozens of community-based research studies with a wide range of research topics, community partners, and levels of community collaboration. Their research addressed a variety of health issues, from chronic and infectious diseases to mental health, injury prevention, and environmental exposures. Our respondents also worked with different community partners, including churches, healthcare providers, social service organizations, advocacy groups, and local government institutions.

From this diversity of experiences, a number of salient themes emerged. These themes captured respondents' understandings of what it means to conduct community-engaged research, the variety of ways they partnered with the community, the challenges they faced and the strategies they used to address these challenges, and the value they found in engaging community partners in research. The rest of this section explores these themes in detail.

Describing Their Work: CBPR vs. Community-based Research

As expected, some respondents clearly located their work within the CBPR approach. They described implementing or being guided by CBPR principles and self-identified as CBPR practitioners. When asked to describe their work, they used words and phrases that illustrated their understanding of CBPR principles.

[Our] studies are participatory, and by that I mean that the beneficiaries of the projects are involved in almost all of the phases of the research. (Female, Assistant Professor)

Other respondents felt that their own community-based research did not necessarily meet CBPR's standards of community engagement.

Some of it doesn't feel very community to me, but I guess it really was.... When you work with the state and they then mandate that everybody does something, it hardly feels like community-based work. (Female, Associate Professor)

Several of these respondents expressed discomfort at being seen as authorities on working with communities and named other faculty members who were "really" doing CBPR. Yet they conducted research that involved community partners and often followed some or many CBPR principles.

Forms of Community Engagement

Respondents engaged communities in a variety of ways that fell along a continuum of involvement and control, from community members serving only in an advisory capacity to participating in the design and implementation of studies, and the analysis of results.

The most common form of community engagement reported by our respondents was working with community advisory boards (CABs). All of our respondents had worked with CABs at some point in their careers, either existing CABs or ones they had helped to create. Many respondents described how CABs served as a "sounding board" for researchers to receive community feedback on their protocols. Several researchers described the CAB's role as a "two-way street," where the CAB facilitated information flow in both directions between the research team and the community.

I think there is an important education that kind of goes in two directions. So we can provide information to the community advisory board ... and I think the community advisory board can be very valuable in facilitating that information kind of being communicated and translated to the community. And vice versa, I think that the community advisory board can kind of inform us investigators about what the concerns are within the community. (Male, Associate Professor)

Often, however, CABs or other community partners took a more active role in the actual design and conduct of studies. In some cases, community members served as members of the research team that oversaw the design and implementation of the study. Across different studies, respondents gave numerous examples of community partners assisting with nearly all aspects of the research process, from identifying research questions, developing the study design, identifying community resources, and recruiting research participants to implementing interventions, collecting data, interpreting findings, and disseminating results in the community. Often researchers felt that with the partnership of community members, these tasks were accomplished more successfully than if they had been done by academic partners alone.

Two other forms of community engagement were also commonly cited: hiring community members as project staff, and holding public meetings in the community about their studies.

Hiring community members as project staff not only brought community voices and experiences into the design and implementation of the research project, but also served as a way to build community capacity and to give back to the community by investing in its members. Similarly, holding public meetings benefited both the community and researchers by providing community education on topics related to the study, creating a forum for community feedback to the research team, and disseminating results in the community.

Challenges

In the course of their community-based research projects, respondents experienced a number of challenges. While many of these challenges were practical in nature, they were often rooted in fundamental social, historical, and professional issues. Four main types of challenges emerged: (1) defining and representing the community, (2) sharing power in the community-academic partnership, (3) overcoming a history of institutional research in the local community that was not perceived to provide direct benefits to the community, and (4) balancing the competing demands of a career in academia, and working within incentive structures that may not always support community-engaged research.

Defining and Representing the Community

Many respondents said it was important to identify and define a community as the first step in conducting community-based research.

I think the first step is to identify a community, however you're going to define community. I mean for us it's been defined as kind of faith-based, as community. But if it's a geographic community or a community of disease or a community of common events—however you're going to construct it—you have to know something about your community and the people in it before you move forward. (Female, Adjunct Professor)

Yet defining the community was a challenge for a number of our respondents. When one respondent was asked to name the most challenging aspect of working with the community, she responded, "It's probably defining it." Some respondents stated that they were unsure if their partnerships with organizations such as community hospitals, public schools, and the juvenile justice department could be considered community-based research because they were unclear whether these organizations fit the definition of community partners.

Respondents voiced the concern that even their more traditional community partners might not adequately represent the community or reflect the diversity of viewpoints within a community. One respondent described a "huge disconnect" between the members of the CAB he worked with and "the people whose doors we knock on." Others noted that the community members on an institutional review board may not necessarily represent the community they are supposed to be speaking for. One respondent described being confronted by members of a community group who were upset that JHMI had chosen to work with another community group and not them.

"What do they [the other group] know about the community?" That is what I heard. "Why did Hopkins pick them, and why are they only working with them, and why weren't we part of that?" (Male, Research Associate)

How to define the community and how to ensure accurate representation of the community seemed to be persistent challenges without easy solutions. Respondents did not suggest responses to these challenges as they did for the other main challenges they experienced. Many respondents, however, were clearly aware of and actively grappling with these issues.

Sharing Power

Faculty members said that trying to maintain a balance of power between themselves and their community partners was very important, but described multiple challenges to sharing power. Respondents recognized that the ways in which research typically is structured— for example, that faculty ultimately control grant resources—create baseline power inequities.

The power division is very, very important.... [O]ur ideal goal is really just being in power equally. Sometimes it's hard when you are the one who's going to bring the money and you are the one who is responsible for reporting to the funding agency for the quality outcome and some of your community partners are challenging you.... You get frustrated and you often forget that, yes ... the power has to be equally distributed. (Female, Associate Professor)

Respondents also believed that, compared to faculty, community members may invest more of their personal time and energy in research partnerships and have more at stake in the outcomes of the research, since it is being conducted in their community.

There's usually this inherent inequality that the university-based person is being paid to be at that meeting at seven o'clock that night. The community representative is not being paid. They're volunteering. The stakes are much higher for the community person because this is actually their community where they live, and what happens there has a bigger impact. The researcher ultimately, if the whole thing falls apart, they get in their car and they drive out to the suburbs or wherever they live, and go home. So there are these inherent inequalities. (Male, Professor)

This quote reflects another common view, that practical power imbalances in research structures may be reinforced by socioeconomic inequalities between academic and community partners.

Some respondents described how even well-intentioned researchers may lapse into stereotypes that frame the community as the less capable partner, creating an additional barrier to equitable collaboration.

There are countless times in which I have heard our investigators use language that suggests to me a hierarchy, and they are the very people who are doing, who say they're doing CBPR, but still view the community as being less knowledgeable, less interested in committees, less sophisticated. (Female, Assistant Professor)

Addressing practical causes of power imbalances as well as attitudes that reinforced these imbalances was challenging. Faculty suggested that the best approach was to try to avoid preventable power imbalances and address others as much as possible by building a good community-academic partnership from the beginning. They recommended sharing both money and decision-making power, fostering open communication between community and academic partners, investing project resources to build capacity in community partners, and clearly defining roles from the outset of the project, either through written protocols or dialogue.

Overcoming a History of Research Perceived to Lack Direct Community Benefits

Underlying the challenges of defining and representing the community and sharing power is a history of strained relations between the local East Baltimore community and JHMI, and community mistrust of the institution. These conditions stem, in large part, from prior JHMI research in the East Baltimore community that was not perceived to provide direct community benefits. Lingering skepticism among some residents about the intentions of JHMI researchers has been reinforced by the institution's expanding footprint in the

community, which has replaced residential blocks with new JHMI buildings, simultaneous with a major urban redevelopment project.

Faculty reported frequently encountering the belief among community members that researchers only want to collect data from the community for their own benefit.

Someone said, "You guys are helicopter researchers. You come in with a helicopter just collecting data and leave with the helicopter.... We're sick and tired of you asking the same questions every other year. [Researchers] are just interested in collecting data, publishing in their peer-reviewed journal, and leaving, with nothing [left] in the community." (Female, Associate Professor)

Some researchers identified this skepticism as a hurdle to forming research partnerships, because "on any individual project you have to generate that level of trust." Others described how community mistrust of researchers also caused stress and burnout among faculty members. As one respondent described the attitudes of some CAB members, she confided,

The "us against them," you know, "we're here because you might do bad things," is draining over a period of many years.... This is hard work, it's not easy work. (Female, Instructor)

A few respondents, however, felt that the perception of community mistrust of research was greater than the reality.

I think it's become a stereotype.... I find there are fewer and fewer [mistrustful community members] and many of them are just citing old myths. And when you ask them about their own experience, they haven't had any.... I accept that there is a history. I also would argue that there [have] been tremendous changes and successes, and it's interesting that the positive stories don't get told as often as the negative stories. (Female, Professor)

Community research partnerships were seen as one way to rectify a history of research that was not perceived to benefit the community, and to build trust between the community and JHMI. "I hope that at least through the work that I do, you know, we're trying to bridge some of the wounds that have occurred hereto-fore," said one respondent. Using participatory methods was also recognized as a way to make research easier to conduct in the future. For example, forming strong and trusting community partnerships might improve participant recruitment in future research and lead to additional research collaborations.

Working within Existing Academic Incentive Structures

Many respondents also cited as challenges academic incentive structures that do not support community-engaged research, and the resulting "competing demands" of a career in academia for researchers who wish to adopt CBPR principles. They described how research grants traditionally do not provide time and resources for developing community-academic relationships, providing services alongside research, compensating community partners, building community capacity, working with the community on advocacy or programmatic efforts based on research findings, or sharing results with the community, all key CBPR practices. Respondents said that, as a result of the limitations placed on how research funds are used, "PIs [principal investigators] are forced to move to the next project as soon as the funding is over."

In addition, respondents described how the significant time and effort required for community-engaged activities competed for time with other academic responsibilities, namely publishing and obtaining grants. Some researchers also mentioned that articles from community-based studies are rarely published in high-impact journals. Yet when it is time

for promotion and tenure review, community-based researchers and traditional researchers are still judged on the same criteria.

The only thing that matters in this place is the money that you bring in and the papers that you publish. Service means nothing and teaching means nothing. So if that is the situation, how can you expect someone who is scrambling constantly to pay their salary to get involved in a community initiative that is going to take a lot of time, require a lot of supervision and not pay anything? (Male, Research Associate)

No one is going to promote you on the basis of promoting or facilitating community relations. They'll pat you on the back. They'll congratulate you. When it's time for promotion, they say, "Where are the papers?" (Male, Assistant Professor)

Because of this incentive structure, one respondent said, "I wouldn't be a Professor here if I'd started out in community-based research." He had received tenure based on other research, and increased his time investment in community-engaged research only after becoming tenured. Two other respondents suggested that under current promotion and tenure policies, perhaps only tenured professors should conduct community-engaged research.

I am a proponent of CBPR, but I have some ambivalence about it. It is very time demanding. And from a career standpoint, for an assistant professor to be doing CBPR research, it is very risky if you're going to make it in the academy. It is risky. I have a lot of ambivalence about suggesting that anyone who is not already tenured go out and do this. But on the other hand, people that are tenured are less likely to do it because it would require a complete change in the way you do things. (Male, Professor)

[You could almost say that] these projects only are to be initiated by tenured professors.... It's obviously sort of tongue in cheek, but the problem is that you potentially create almost insurmountable conflicts of interest when somebody comes into the community and knows that they are under the gun to create, to develop publishable data within a certain amount of time, and that their very livelihood depends on it. (Male, Professor)

Respondents who did not self-identify as CBPR researchers were more likely to believe that applying CBPR principles was "risky" for one's career as an academic. These respondents conducted community-based research as a portion of their work, but not as their entire research portfolio. In addition, some described how they had cut short community-engaged projects that were not progressing in such a way that they would produce publishable findings.

Among respondents who self-identified as CBPR researchers, several described ways in which they were able to use academic resources to support CBPR methods. For example, some received technical and moral support from peers who were also using CBPR methods, as well as from academic administrators whose attitudes influence their work.

I think like-minded individuals within the Hopkins community, that we provide structure and support for each other. And you seek out and you find those individuals.... But it's kind of informal. (Female, Associate Professor)

The division finds it important that we do this type of research, so it's well accepted among our colleagues.... It's very easy to do this type of research where I'm doing it. It's not that you have to make a point that it's important. People understand that it is, and accept it. (Female, Research Associate)

Some of these respondents also described how they were creative in their use of existing funding sources to support CBPR methods. For example, they described using small seed grants to support partnership development, or funds for staff training to build capacity in community partners.

Several researchers suggested that changes to academic incentive structures would encourage greater use of CBPR approaches. Some described a promising trend in which an increasing number of federal and private grants now require community partnerships, and sometimes provide funds to support partnership development and maintenance. A few respondents mentioned changes in promotion and tenure policies at other institutions that recognize differences between community-engaged research and traditional research. They suggested that these approaches should be encouraged at JHMI as well. One argued that the best way to ensure institutional support for community-based research would be to create a dedicated center, consortium, or other formal organization for community-engaged research.

The question is... how should Hopkins reorganize to do community-based research? So, for example, it has a laboratory infrastructure for doing bench research. If we were going to be a center for community-based research, we would need ... the equivalent of that infrastructure. (Male, Professor)

Respondents argued that the adoption of these strategies could improve support for community-engaged research at JHMI. However, they also believed that academic incentive structures are "a bigger problem than any one institution" and that the priorities of "the academy in general" would have to shift in order for real change to occur.

Expanding the Definition of Success in Research

While respondents described multiple challenges, the majority felt that their community-based work had been successful. Many respondents mentioned how community engagement had improved the success of their research according to traditional measures, such as high rates of enrollment and retention or "completing the study as outlined." Several respondents described how community involvement had improved the quality of their research, enhanced their understanding of their research topics, and resulted in "a far richer product than we could have imagined, envisioned, or been able to do without them."

Yet several respondents felt that traditional measures of research success were too narrow to judge the success of community-based research.

I think that to be a truly collaborative person, you have to be able to go into it and say, "I can't be thinking of grants and papers as the primary means of judging whether this is a success or not. I can have faith that ultimately those things will come, because they are the currency of my career. But I have to realize that they're not the way in which the success of this collaboration is necessarily going to be judged [by the community]." (Male, Professor)

This respondent also suggested that applying only traditional measures of success to judge community-based research could lead researchers to conduct their work in the wrong way, undermining their ability to be collaborative or to prioritize the community's needs, both central values of CBPR.

The most commonly discussed non-traditional definition of success was building relationships. "I think the success is always in the relationship," said one respondent. Respondents saw building relationships as a key goal of community-based research, since relationships could develop into lasting partnerships that might improve relations between the community and the institution, leading to additional collaborations.

Other respondents said that their research was successful because it invested in the community or built community capacity, for example, by increasing the availability of health or social services, improving community health status, or hiring and training community members. Several respondents saw these investments in the community as contributing to social justice.

A number of researchers described how forming strong relationships and conducting research that addressed community needs gave them a feeling of personal satisfaction.

There is just a humanity payoff, just a feeling good about your research when you're able to share it with people that might be affected by it. So it's sort of intangible I guess. (Female, Instructor)

I think we did it in a good way, so we got a positive response, not only from the community centers, but also from the people who pertained to the community centers. That was very positive. We left with a good feeling. (Female, Research Associate)

CBPR as a Journey

Many faculty members who engage in CBPR have come to see it not as a research method that must be implemented either in its entirety or not at all, but instead as a set of guiding principles that can be applied to varying degrees (Israel et al., 1998). Respondents in our study reflected this point of view.

So I think there's a full range [of potential community involvement] from advisory to complete control, that continuum, and ... at some point [you want to] be able to get to the end, the upper end of that continuum. (Female, Adjunct Professor)

Many respondents, including those who did and did not self-identify as CBPR researchers, felt that they had progressed along this continuum as they gained experience and built relationships over successive community-based studies.

As the projects progress, the community engagement has gotten more and more involved. So initially it was bringing in an advisory team to help us shape and focus surveys and projects, and this more recent project really is much more in depth, where the [community group] is participating with more decision-making, I'd say, and control. (Female, Adjunct Professor)

This trajectory was underscored by faculty members who described their experiences as a process or journey. They also said that the entire field of CBPR was still progressing, and that, in practice, community-based researchers were still working to catch up to the CBPR principles.

Let me say first that my work in this area is still developing and being refined, and not all of the work that I have done has been exactly as I would have liked for it to be. With each project, there is refinement that is taking place, and I see this still as a journey. So ... I think for those of us who do CBPR research, that we need to understand that we haven't quite arrived, haven't really run into anybody that's really done this in the way that the principles say it should happen. (Female, Assistant Professor)

Despite encountering a variety of challenges when conducting community-engaged research, overall our respondents were optimistic about implementing CBPR principles in their research. "The point is, you can do it," said one. Respondents thought that community involvement could be "mutually beneficial and a win-win" situation for both communities and researchers. They believed that a participatory approach could enhance the quality of

research, improve community-academic relations, and help address social injustices. Defining success in non-traditional terms that included building relationships and investing in the community left faculty members with a sense of satisfaction. "It's been a very happy experience," said one respondent. Another said simply, "I love it."

Discussion

This is the first study we are aware of to use qualitative methods to explore faculty members' perspectives on community-based research across a broad range of research projects. Our findings demonstrate the diversity of faculty experiences with community engagement in research. The extent to which CBPR principles are applied in any given study depends on multiple factors, including faculty members' training and priorities, lessons learned from past research experiences, the nature of the research questions, and community capacity for partnerships. Although they might not yet be implementing all CBPR principles, the faculty members who participated in this study are taking important steps toward community engagement, and many voiced a commitment to progressing along this continuum. Our study highlights the challenges that researchers experience as they engage in this process, and how they have responded.

The themes discussed by our respondents are consistent with those found in the existing literature on community-based research. Across a wide variety of projects and locations, from Detroit (Lantz et al., 2001) to Seattle (Eisinger & Senturia, 2001) to New York (Freudenberg, 2001), researchers engaged in community partnerships have encountered very similar challenges and have recommended similar responses (Metzler et al., 2003; Israel et al., 2006). Our respondents may have been echoing themes they had encountered in the literature, or existing scholarly work may have provided them with a frame for understanding their current experiences. However, the themes that emerged from these interviews are also consistent with findings from our survey of JHMI faculty and staff and our qualitative study with East Baltimore community members (Farfel, Goldberg-Freeman, & Vogel, 2005; Goldberg-Freeman et al., 2007). In our faculty survey, respondents overwhelmingly agreed that involving community partners improves the quality (85%) and relevance (91%) of research, but significant numbers also agreed that community involvement is fraught with problems (60%) and is too time consuming (41%). Our study with East Baltimore community members also found that widespread perceptions of a negative history of interactions between JHMI researchers and the East Baltimore community had made community members skeptical of research. However, the study also highlighted community members' views on the importance of being involved at all stages of research, the trust gained from community involvement in research, and the desire for research collaborations to lead to community capacity-building and sustainable programs. The level of agreement between these studies and the published literature suggests that the major benefits and challenges of community-engaged research, and the strategies being used to address these challenges, are widespread and consistent.

Although we did not specifically ask respondents about ethical issues or frame questions in ethical terms, their responses did point to linkages between CBPR and ethical principles. For example, several respondents noted the role that CBPR can play in achieving social justice by helping to develop resources, build capacity in participating communities, and redress a history of research that may not have had direct benefits for participating communities. These goals correspond with the ethical principles of beneficence and justice. Our respondents also raised the concern that community partners might not adequately represent the community. Seen through an ethical lens, this issue might be considered a justice concern. At least one respondent suggested that existing academic incentive structures might "create almost insurmountable conflicts of interest" and lead researchers to conduct their

research in ways that are both less ethical and less faithful to the CBPR approach. The links between ethical principles and CBPR principles suggest that highlighting the ways that CBPR improves the ethics of research may help CBPR gain greater acceptance in academic settings.

The results of this study should be considered in light of its limitations, which are similar to those of qualitative research in general. Our findings may not be generalizable to other settings or to other researchers at JHMI because we did not attempt to recruit a representative group of JHMI faculty. Rather, we purposefully selected interview respondents in order to ensure a diversity of perspectives and experiences in our sample.

Best Practices

We believe that this study, in conjunction with the existing literature on community engaged research, helps identify concrete ways in which funding agencies and academic institutions can support researchers as they translate CBPR principles into practice.

Funding agencies can institute requirements for involving communities in research and provide financial support for these aspects of research studies, such as creating partnerships and disseminating findings in the community. Our interviews suggested that such policies can and do work to encourage community engagement. For example, several respondents described working with federally-mandated CABs as their main form of community engagement. Others described working with community partners because of new grant requirements.

Academic institutions can also adopt policies and implement initiatives to support CBPR. They can revise promotion and tenure review policies to recognize and reward community-engaged research. Guidelines for review of promotion and tenure policies have been proposed previously (Mikkelsen et al., 2005). Our respondents suggested that revising these policies would encourage young researchers to adopt the CBPR approach and help researchers already following CBPR principles to remain dedicated to the approach. In addition, increasing formal opportunities for training and mentoring in CBPR philosophy and methods can encourage new and mid-career researchers to adopt this approach. Initiatives such as the Kellogg Health Scholars post-doctoral fellowship program can serve as models for this type of mentoring and training (Kellogg Health Scholars, 2009). Some respondents also suggested structural changes that would support community engagement in research, such as creating an institutional center for CBPR or requiring community involvement in all protocols submitted to an institutional review board.

The literature proposes additional ways to provide institutional support for CBPR. For example, Quinn (2004) has noted that while CABs generally are created for a single study, some institutions have created free-standing CABs that serve multiple studies across the institution. This permanent infrastructure to support community engagement could encourage investigators who are interested in applying CBPR principles but concerned about the time required to establish partnerships from the ground up.

In short, academic institutions and funding agencies can foster faculty involvement in community-engaged research in multiple ways, particularly through the adoption of new policies and the development of structural and programmatic supports. Community-Campus Partnerships for Health (2009) has gathered a wide range of resources for funding agencies, academic institutions, and individual researchers seeking to foster research partnerships with communities. In addition, emphasizing the links between CBPR and ethical principles may encourage institutions to support the CBPR approach.

Research Agenda

This research highlights a number of key challenges related to the adoption of the CPBR approach, including how best to define and ensure adequate representation of communities, how to balance power in community-academic partnerships, and how to work within academic incentive structures that do not adequately support the CBPR approach. These challenges are not easily resolved, but sharing successful strategies and approaches from ongoing partnerships will add to our collective knowledge of how to address these challenges and maximize our fidelity to CBPR principles. As funding agencies and academic institutions increasingly implement policies or initiatives to support or, in some cases, require community engagement in research, rigorous evaluation of these policies should be undertaken to assess whether their goals and objectives are realized.

Educational Implications

In the past decade, significant advances have been made in communicating the rationale behind CBPR principles and the benefits of the CBPR approach to both community and academic partners. These have led to the incorporation of CBPR methods into public health training, such as the Masters of Public Health curriculum from the Association of Schools of Public Health and post-doctoral training opportunities such as the Kellogg Health Scholars program described above. The findings from this study strongly support these efforts and suggest that they will encourage new researchers to follow CBPR principles. However, our findings also highlight the challenges that CBPR poses to academic career advancement and the ethical conflicts that may arise from the competing demands of academic promotion and community engagement. Several respondents suggested that achieving tenure could alleviate some of these concerns but noted that once tenured, faculty members may find it difficult to change their approach to research. Therefore, CBPR training and mentoring opportunities should be provided for faculty at multiple stages of career development.

The JHMI faculty members we interviewed are paradigmatic of a national body of researchers engaging in increased collaboration with communities in health sciences and public health research. Nationally, this trend is manifested in the growing availability of grant funding for CBPR approaches and revisions to promotion and tenure policies at some universities to recognize community-engaged research (Nyden, 2003; Portland State University, 1996). Yet this trend is being led on the ground level by researchers and their community partners who are working through the challenges of collaboration to produce research that is as relevant to communities as it is to scientists. These individuals can serve as models for others who would like to adopt the CBPR approach. Their experiences provide opportunities for knowledge-sharing and can help identify concrete ways in which community-engaged research can be supported. Lessons learned from these experiences should be widely disseminated to address the challenges in community-engaged research and improve the chances of future success.

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Appendix I. Interview Guide Questions

Professional Background

• To start out, tell me about your position at Hopkins.

Experiences Engaging in Community-based Research and Community-Academic Partnerships

- Tell me about your experience working with the East Baltimore community.
- Thinking about all of your research studies in East Baltimore, what motivated you to work with the East Baltimore community?
- Thinking about all your research experiences in East Baltimore, in what ways have community members or organizations been involved in the research process?

Ingredients of Successful Community-based Research

- Tell me about your most successful research experiences working with the East Baltimore community. What made them successful?
- What do you think the ideal community-based research project in East Baltimore would look like?

Challenges Faced in Community-based Research and Related Recommendations

- I asked you earlier to tell me about a successful experience. Now I want you to think back to the more challenging projects or parts of a project that you have experienced. What were some of those challenges? How have you addressed those challenges?
- What advice would you give to a colleague who is considering embarking on research in East Baltimore for the first time?
- We are interested in supporting the dissemination of community-based research findings to community members. What do you think are some of the barriers to that?

Support for Future Community-based Research at JHMI

- Now taking a step back from your own experiences and perceptions, what do you
 think are the general attitudes of Hopkins researchers about conducting research in
 the East Baltimore community?
- How do you think the East Baltimore community views Hopkins researchers?
- (If appropriate:) How would you address the negative attitudes you mentioned?
- Thinking back to what you said earlier about challenges you've had with the community, what advice would you give to community members, leaders, or organizations about how to support community-based research?
- Thinking back to what you said earlier about challenges you've had with Hopkins, what do you think they can do to support community-based research at the school?
- As a product of this study, we would like to develop educational resources about East Baltimore and community-based research for Hopkins researchers. What information would you share? What format would you suggest?

How to Improve Community Representation in Community-based Research Review

One suggestion is that in addition to the Hopkins IRBs, there should be a
community review board that would evaluate proposed studies in East Baltimore.
All studies would have to be approved by the community board in addition to the
Hopkins IRBs. What do you think about that idea?

Snowball Sampling

• Can you suggest names of other Hopkins researchers we should interview about their experiences with community-based research?

References

- Ahmed SM, Beck B, Maurana CA, Newton G. Overcoming barriers to effective community-based participatory research in US medical schools. Education for Health. 2004; 17(2):141–151. [PubMed: 15763757]
- Astin, AW. Promoting leadership, service and democracy: What higher education can do. In: Bringle, RG.; Games, R.; Malloy, EA., editors. Colleges and Universities as Citizens. Boston, MA: Allyn and Bacon; 1999. p. 31-47.
- Baltimore City Health Department. Communities in Charge. 2000. Retrieved July 9, 2006 from http://www.communitiesincharge.org/Phase%20One/Baltimore.htm #Demographics
- Bloor, MJ. Notes on member validation. In: Emerson, RM., editor. Contemporary Field Research: A Collection of Readings. Prospect Heights, IL: Waveland Press, Inc; 1988. p. 156-172.
- Boyer, EL. Scholarship Reconsidered: Priorities of the Professoriate. San Francisco: Jossey-Bass; 1990
- Bringle, RG.; Games, R.; Malloy, EA. Colleges and universities as citizens: Reflections. In: Bringle, RG.; Games, R.; Malloy, EA., editors. Colleges and Universities as Citizens. Boston, MA: Allyn and Bacon; 1999. p. 193-204.
- Cohen, C. Far from home: Wisconsinite takes helm at Save Middle East Action Committee. Baltimore City Paper. 2007 January 31. Retrieved September 30, 2007 from http://www.citypaper.com/printStory.asp?id=13201
- Community-Campus Partnerships for Health. Principles and Best Practices for Healthier Communities Conference Proceedings; April 25–28, 1998; Pittsburgh, PA. 1999. Available online at http://depts.washington.edu/ccph/pdf_files/98PROCED.pdf
- Community-Campus Partnerships for Health. Resources. 2009. Retrieved April 4, 2009 from http://www.ccph.info
- De Koning, K.; Martin, M. Participatory research in health: Setting the context. In: De Koning, K.; Martin, M., editors. Participatory Research in Health: Issues and Experiences. London: Zed Books; 1996. p. 1-18.
- Eisinger A, Senturia K. Doing community-driven research: A description of Seattle Partners for Healthy Communities. Journal of Urban Health. 2001; 78(3):519–534. [PubMed: 11564854]
- Emanuel EJ, Wendler D, Killen J, Grady C. What makes clinical research in developing countries ethical? The benchmarks of ethical research. Journal of Infectious Diseases. 2004; 189(5):930–937. [PubMed: 14976611]
- Farfel, M.; Goldberg-Freeman, C.; Vogel, A. Academic-researchers' experiences with community-based research: A quantitative and qualitative study of Johns Hopkins Medical Institution Faculty. Program and Abstracts of the American Public Health Association 133rd Annual Meeting; December 10–14; Philadelphia, PA. 2005. Abstract available online at http://apha.confex.com/apha/133am/techprogram/paper_114189.htm
- Farfel MR, Orlova AO, Lees PJS, Rohde C, Ashley PJ, Chisolm JJ Jr. A study of urban housing demolitions as sources of lead in ambient dust: Demolition practices and exterior dust fall. Environmental Health Perspectives. 2003; 111(9):1228–1234. [PubMed: 12842778]
- Fox CE, Morford TG, Fine A, Gibbons MC. The Johns Hopkins Urban Health Institute: A collaborative response to urban health issues. Academic Medicine. 2004; 79(12):1169–1174. [PubMed: 15563651]
- Freudenberg N. Case history of the Center for Urban Epidemiologic Studies in New York City. Journal of Urban Health. 2001; 78(3):508–518. [PubMed: 11564853]
- Goldberg-Freeman C, Kass NE, Tracey P, Ross G, Bates-Hopkins B, Purnell L, Canniffe B, Farfel M. "You've got to understand community": Community perceptions on "breaking the disconnect" between researchers and communities. Progress in Community Health Partnerships: Research, Education, and Action. 2007; 1(3):213–214.

Gomez MB, Muntaner C. Urban redevelopment and neighborhood health in East Baltimore, Maryland: The role of communitarian and institutional social capital. Critical Public Health. 2005; 15(2):83–102.

- Green, LW. Tracing federal support for participatory research in public health. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 410-418.
- Green LW, Mercer SL. Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? American Journal of Public Health. 2001; 91(12):1926–1929. [PubMed: 11726367]
- Higgins DL, Metzler M. Implementing community-based participatory research centers in diverse urban settings. Journal of Urban Health. 2001; 78(3):488–494. [PubMed: 11564851]
- Israel BA, Krieger J, Vlahov D, Ciske S, Foley M, Fortin P, Guzman JR, Lichtenstein R, McGranaghan R, Palermo A, Tang G. Challenges and facilitating factors in sustaining community-based participatory research partnerships: Lessons learned from the Detroit, New York City, and Seattle Urban Research Centers. Journal of Urban Health. 2006; 83(6):1022–1040. [PubMed: 17139552]
- Israel BA, Parker EA, Rowe Z, Salvatore A, Minkler M, López J, et al. Community-based participatory research: Lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. Environmental Health Perspectives. 2005; 113(10):1463–1471. [PubMed: 16203263]
- Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. Annual Reviews of Public Health. 1998; 19:173–202.
- Israel BA, Schulz AJ, Parker EA, Becker AB. Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. Education for Health. 2001; 14(2):182–197. [PubMed: 14742017]
- Israel, BA.; Schulz, AJ.; Parker, EA.; Becker, AB.; Allen, AJ.; Guzman, JR. Critical issues in developing and following community-based participatory research principles. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 53-76.
- Kellogg Health Scholars. Overview. 2009. Retrieved April 4, 2009 from http://www.kellogghealthscholars.org
- Lantz PM, Viruell-Fuentes E, Israel BA, Softley D, Guzman R. Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit. Journal of Urban Health. 2001; 78(3):495–507. [PubMed: 11564852]
- Lee, PT.; Krause, N.; Goetchius, C. Participatory action research with hotel room cleaners: From collaborative study to the bargaining table. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 390-404.
- Maxwell, JA. Qualitative Research Design: An Interactive Approach. Thousand Oaks, CA: Sage Publications; 1996.
- Metzler MM, Higgins DL, Beeker CG, Freudenberg N, Lantz PM, Senturia KD, Eisinger AA, Viruell-Fuentes EA, Gheisar B, Palermo AG, Softley D. Addressing urban health in Detroit, New York City, and Seattle through community-based participatory research partnerships. American Journal of Public Health. 2003; 93(5):803–811. [PubMed: 12721148]
- Mikkelsen, M.; Gelmon, SB.; Seifer, SD.; Kauper-Brown, J. Community-Engaged Scholarship for Health Collaborative: Review, Promotion, and Tenure Policy Analysis Protocol. Seattle, WA: Community-Campus Partnerships for Health; 2005.
- Minkler M. Community-based research partnerships: Challenges and opportunities. Journal of Urban Health. 2005; 82(Suppl. 2):ii3–ii12. [PubMed: 15888635]
- Minkler M, Blackwell AG, Thompson M, Tamir H. Community-based participatory research: Implications for public health funding. American Journal of Public Health. 2003; 93(8):1210–1213. [PubMed: 12893597]

Minkler M, Vásquez VB, Shepard P. Promoting environmental health policy through community-based participatory research: A case study from Harlem, New York. Journal of Urban Health. 2005; 83(1):101–110. [PubMed: 16736358]

- Minkler, M.; Wallerstein, M. Introduction to community-based participatory research. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 3-26.
- Morse, JM.; Richards, L. Readme First for a User's Guide to Qualitative Methods. Sage Publications; Thousand Oaks, CA: 2002.
- Nyden P. Academic incentives for faculty participation in community-based participatory research. Journal of General Internal Medicine. 2003; 18(7):576–585. [PubMed: 12848841]
- O'Fallon LR, Dearry A. Community-based participatory research as a tool to advance environmental health sciences. Environmental Health Perspectives. 2002; 110(Suppl. 2):155–159. [PubMed: 11929724]
- Parker EA, Israel BA, Williams M, Brakefield-Caldwell W, Lewis TC, Robins T, Ramirez E, Rowe Z, Keeler G. Community action against asthma: Examining the partnership process of a community-based participatory research project. Journal of General Internal Medicine. 2003; 18(7):558–567. [PubMed: 12848839]
- Portland State University. Policies and Procedures for the Evaluation of Faculty for Tenure, Promotion, and Merit Increases. 1996. Adopted by the PSU Faculty Senate June 12, 1996. Retrieved November 9, 2007 from http://www.pdx.edu/oaa/promotion-tenure-guidelines
- Quinn SC. Ethics in public health research: Protecting human subjects: The role of community advisory boards. American Journal of Public Health. 2004; 94(6):918–922. [PubMed: 15249289]
- Seifer, S. Documenting and assessing community-based scholarship: Resources for faculty. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 429-443.
- Seifer SD, Calleson DC. Health professional faculty perspectives on community-based research: Implications for policy and practice. Journal of Interprofessional Care. 2004; 18(4):416–427. [PubMed: 15801556]
- Sullivan M, Kone A, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW. Researcher and researched-community perspectives: Toward bridging the gap. Health Education and Behavior. 2001; 28(2): 130–149. [PubMed: 11265825]
- Viswanathan, M.; Ammerman, A.; Eng, E.; Gartlehner, G.; Lohr, KN.; Griffith, D., et al. Evidence Report/Technology Assessment No 99, AHRQ Publication 04-E022-2. Rockville, MD: Agency for Healthcare Research and Quality; 2004. Community-based Participatory Research: Assessing the Evidence. Available online at http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf
- Wallerstein, N.; Duran, B. The conceptual, historical, and practice roots of community-based participatory research and related participatory traditions. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 27-52.
- Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. Health Promotion Practice. 2006; 7(3):312–323. [PubMed: 16760238]

Biographies

Caitlin Kennedy, M.P.H., is a Ph.D. Candidate in the Department of International Health, Social and Behavioral Interventions Program at the Johns Hopkins Bloomberg School of Public Health. Her research examines behavioral interventions for HIV/AIDS in resource-limited settings, research ethics, and community participation in research with a focus on qualitative methods.

Amanda Vogel, M.H.S., is a Ph.D. Candidate in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. She has implemented and evaluated community-based health promotion programs in underserved urban areas. Her current research uses qualitative methods to investigate how academic and

community partners can best foster and sustain mutually beneficial partnerships for research, teaching, and capacity building.

Clara Goldberg-Freeman, M.H.S., C.H.E.S., worked as project manager of the Environmental Justice Partnership for five years. The Partnership's main objective is to develop equitable and sustainable dialogue and partnerships between the university's researchers and the various communities of East Baltimore. As project manager, Clara's main role was to strategize and facilitate capacity-building activities for community and academic partners to increase collaborative and equitable research partnerships. She is currently at home raising her son.

Nancy Kass, Sc.D., is the Phoebe R. Berman Professor of Bioethics and Public Health at the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins Berman Institute of Bioethics. Dr. Kass conducts empirical research in bioethics, public health, and health policy. Her publications address HIV/AIDS policy, genetics policy, public health ethics, informed consent, and U.S. and international research ethics.

Mark Farfel, Sc.D., was Professor of Health Policy and Management and Environmental Health at the Johns Hopkins School of Public Health at the time of this study. He helped found InterAction, a program to help Johns Hopkins medical students become more effectively involved in community service and social justice activities. His research focused on disease prevention with vulnerable populations, urban environmental health, community health, and environmental justice. He is currently Director of the World Trade Center Health Registry, Division of Epidemiology, in the New York City Department of Health and Mental Hygiene.

Table 1

Characteristics of Interview Participants (n = 22).

Characteristics	Number
Primary Institutional Affiliation at JHMI	
Bloomberg School of Public Health	12
School of Medicine	6
School of Nursing	3
Kennedy Krieger Institute*	1
Position	
Non-tenured faculty	14
Tenured faculty	8
Role in Community-engaged Research	
Principal investigator	15
Not principal investigator	7
Research Locations	
East Baltimore	20
Other Baltimore neighborhoods	22
Gender	
Female	12
Male	10
Race/Ethnicity	
White	13
Black or African American	6
Asian	2
Latino	1

^{*}Kennedy Krieger Institute is a non-profit independent affiliate specializing in pediatric disorders of the brain and spinal cord.