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Variation in the Interpretation of Scientific Integrity in Community-based Participatory Health Research

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Abstract

Community-based participatory research (CBPR) has become essential in health disparities and environmental justice research; however, the scientific integrity of CBPR projects has become a concern. Some concerns, such as appropriate research training, lack of access to resources and finances, have been discussed as possibly limiting the scientific integrity of a project. Prior to understanding what threatens scientific integrity in CBPR, it is vital to understand what scientific integrity means for the professional and community investigators who are involved in CBPR.

This analysis explores the interpretation of scientific integrity in CBPR among 74 professional and community research team members from of 25 CBPR projects in nine states in the southeastern United States in 2012. It describes the basic definition for scientific integrity and then explores variations in the interpretation of scientific integrity in CBPR. Variations in the interpretations were associated with team member identity as professional or community investigators. Professional investigators understood scientific integrity in CBPR as either conceptually or logistically flexible, as challenging to balance with community needs, or no different than traditional scientific integrity. Community investigators interpret other factors as important in scientific integrity, such as trust, accountability, and overall benefit to the community. This research demonstrates that the variations in the interpretation of scientific integrity in CBPR call for a new definition of scientific integrity in CBPR that takes into account the understanding and needs of all investigators.

Introduction

Community-based participatory research (CBPR) emphasizes the importance of community members participating in every step of the research process (Israel, Parker, & Rowe, 2005; Wallerstein & Duran, 2006). CBPR prescribes an equitable partnership between professional and community investigators in all research responsibilities (Israel, Schulz, Parker, & Becker, 1998, Israel et al., 2003), emphasizing the importance of co-education and

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rectification of knowledge imbalances between professional and community investigators (Leung, Yen, & Minkler, 2004). CBPR should lead to social change in addition to producing knowledge (Minkler & Wallerstein, 2003). It requires interdisciplinary collaborations that transcend traditional academic frameworks and create equal partnerships between professional and community investigators (Minkler, 2004). It recognizes that power imbalances between professional and community investigators in traditional research have limited community members to the roles of information providers who seldom receive the benefit of research findings; this has created mistrust and resentment towards research (Israel et al., 2005; Leung et al., 2004; O'Fallon & Dearry, 2002; Savage et al. 2006). CBPR changes the traditional research paradigm and emphasizes sharing power between professional and community investigators to build trust (Holkup, Tripp-Reimer, Salois, & Weinert, 2004; Wallerstein, 1999).

CBPR is essential in health disparities and environmental justice research (Khanlou & Peter, 2005; Leung et al. 2004; Quandt, Arcury & Pell, 2001). CBPR projects often focus on health concerns among vulnerable populations. This approach helps investigators obtain internally valid, culturally specific insights into the social and environmental contexts surrounding health and disease through the involvement of community members. These insights facilitate development of conceptually tailored and culturally appropriate interventions, with CBPR being promoted as an appropriate means to translation science (Leung et al. 2004; Wallerstein & Duran 2010).

The literature describing CBPR has focused on factors that affect community-research relationships and project success (Arcury, Quandt & Dearry, 2001; Israel et al., 2005; Minkler, 2004; Quandt et al., 2001). However, scientific integrity in CBPR projects has also become a concern (Hueston et al., 2006; Minkler, 2004; Wallerstein & Duran, 2006). Scientific integrity can be understood as a set of professional standards and as an ethical obligation (Coughlin, Barker, & Dawson, 2012). A familiar definition focusing on standards is, "adherence by scientists and their institutions to honest and verifiable methods in proposing, performing, evaluating, and reporting research activities" (Panel on Scientific Responsibility and the Conduct of Research, 1992, p.4). A second definition explores the ethical obligation for scientists and institutions "… integrity embodies above all the individual's commitment to intellectual honesty and personal responsibility. It is an aspect of moral character and experience. For an institution, it is a commitment to creating an environment that promotes responsible conduct by embracing standards of excellence, trustworthiness, and lawfulness and…if an environment with high levels of integrity has been created" (Institute of Medicine, 2002, p.4).

The discussion of research integrity and CBPR is growing, but has focused on case studies and literature reviews (Buchanan, Miller, & Wallerstein, 2007; Cargo & Mercer, 2008; Horowitz, Robinson, & Seifer, 2010; Hueston et al., 2006; Minkler, 2004; Viswanathan, 2004). Concerns about scientific integrity in CBPR include study design, conflicts of interests, and facilitating ethical review by institutional review boards. Buchanan and colleagues (2007) explain that due to structural impediments inherent in CBPR, randomized controlled trials, the gold standard for rigorous scientific research, often are not possible; while quasi-experimental or one-group designs are often feasible. Resnik and Kennedy (2010) explore balance in the interests between the scientists and the community as a challenge for CBPR. Hueston and colleagues (2006) examine how IRBs and the participating community can both be knowledgeable in review and approval processes.

The majority of discussions of scientific integrity in CBPR highlight three primary areas of concern. First, project team members have variable norms, expectations, and agendas that are connected to their associations with different disciplines, cultures, and communities.

Second, team members have different amounts of research training and methodological expertise. Third, team members have different access to resources (time, money, equipment, staff) (Buchanan et al., 2007; Cargo & Mercer, 2008; Horowitz, et al. 2010; Hueston et al., 2006; Minkler, 2004; Quandt et al., 2001; Viswanathan, 2004). These concerns may limit the soundness of CBPR. For instance, a lack of access to time, money, and appropriate research training could limit the scientific integrity of a project by making it impossible to recruit the appropriate participants and complete data collection as specified in the study protocol. Commonly suggested methods to improve scientific integrity include maintaining open and frank dialogue among team members about community needs, the criteria for rigorous science, and how to serve community and scientific interests, perhaps, through mutual compromise; clearly delineating team members' roles and maintaining respect for each member's unique talents, skills, and areas of expertise; and purposefully initiating co-learning between team members that balances team members' knowledge and skills (Buchanan et al., 2007; Cargo & Mercer, 2008; Wallerstein & Duran, 2006).

CBPR is currently not evaluated by any set of specific criteria; however, lists of principles have established the foundation for CBPR (Blumenthal, 2011; Green et al., 1995; Israel et al. 1998, 2005; Viswanathan, 2004). Yet, only one of these lists considers scientific rigor as a concern for CBPR (Viswanathan, 2004). Systematic inquiry into the meaning and interpretation of scientific integrity in CBPR has not been reported. It is vital to understand what scientific integrity means for professional and community investigators involved in CBPR prior to suggesting that scientific integrity is threatened and specifying how it may be threatened. This paper explores variations in the interpretations of scientific integrity in CBPR among a sample of professional and community CBPR investigators.

Methods

This investigation used a qualitative design to delineate perspectives on scientific integrity for CBPR investigators conducting projects in the southeastern US. Interviews were conducted with professional and community investigators from 25 separate projects. Data collection was completed in 2012. The research protocol was approved by the Wake Forest School of Medicine IRB, and all participants provided signed consent.

Participants

A list of currently funded CBPR projects in the southeastern US (Virginia, Kentucky, North Carolina, South Carolina, Georgia, Florida, Mississippi, Alabama, Louisiana, Puerto Rico) was compiled from the NIH Reporter (http://projectreporter.nih.gov/reporter.cfm) (90 projects across all NIH Institutes and Centers) and the CDC Prevention Research Centers website (http://www.cdc.gov/prc/) (8 centers). All projects whose abstracts indicated they were funded, at least in part to conduct community-based participatory research were included in the inquiry. The contact principal investigators (PIs) from 50 projects were randomly selected by state and stratified by environmental disease or chronic health topics. PIs were invited to participate in this study, with the goal of recruiting 25 projects, such that half were focused on environmental health issues and half were focused on a chronic disease. Of the 50 PIs contacted, nine failed to reply, and eight declined to participate (Table 1). Of the 33 who expressed interest in participating, two projects involved communities geographically located outside the Southeast, two were early in their development, three accepted after the goal of 25 had been achieved, and one agreed to participate but was later unable due to a natural disaster. The 25 participating CBPR projects in the final sample included 13 focused on environmental health and 12 studies focused on chronic disease (Table 2). Nine focused on communities of mixed ethnicities, 11 focused on largely African-American communities, and 5 focused on immigrant or refugee populations. This sample

and recruitment design attempted to understand differences among projects working in specific research topics and with specific target populations.

Contact PIs (all professional) were asked to complete an interview and suggest two team members with good knowledge of the project (at least one community investigator) to complete interviews. Participants included 34 professional investigators (professionally trained in research, that work in academia, a non-profit, or practice-based research networks), 10 academic-community liaisons (community members employed by the university), and 33 community investigators (have diverse backgrounds in research training, involved as an individual or as part of a community-based organization) (Table 3). Partnerships between professional and community investigators ranged from 1 to 13 years (average of 6.6 years). All participants had to be at least 18 years old and fluent in English or Spanish.

Data Collection

Data were collected through in-depth, semi-structured interviews. All but one interview was conducted in person, with interviewers traveling to the locations of the participants; the last interview was conducted by phone. Participants received a $20 incentive. Interviews consisted of general questions about occupational and educational background, experience with CBPR, and perspectives on CBPR and scientific integrity. The draft guide was reviewed by the project advisory committee (composed of 15 CBPR investigators from outside the southeastern US), and five pilot interviews were conducted (3 English, 2 Spanish). The interview guide was revised with advisory committee feedback and the experience of the pilot interviews. Throughout data collection, the investigators reviewed the interview recordings and met to discuss any variations from the original interview guide.

Analysis

All interviews were audio recorded and transcribed verbatim. The transcripts were edited for accuracy and to remove identifying personal information. Each team member identified themes, patterns, and issues present in the narratives. Themes, patterns, and issues were discussed by the team and formed the basis for a coding dictionary. Transcripts were coded by at least two research team members and were subjected to saliency analysis with the aid of Atlas.ti qualitative data analysis software (ATLAS.ti Scientific Software Development GmbH, Berlin). Saliency analysis was completed by assessing the thematic patterns across all of the interviews and evaluating recurrent themes based upon their frequency of recurrence, the participants' emphasis on the themes, or descriptive capacity of the theme recognized by the research team (Arcury, Quandt, & Bell, 2001; Buetow, 2010; Quandt et al., 2001). Salient themes may not have been discussed by every individual; but they were discussed in detail and with emphasis throughout the sample or were found to provide some insight or explanation of a given phenomenon. Through this iterative process, quotations that demonstrate the understanding of scientific integrity and its application within CBPR were identified; and noted themes were listed according to frequency, participant's emphasis, and explanatory capacity.

Results

Scientific Integrity

Definitions of scientific integrity were very similar across professional and community investigators. Community investigators described scientific integrity as having uniform methods, with consistent results, and that investigators were honest by presenting all of their findings. Professional investigators' definitions tended to be longer and more detailed, but mirrored those provided by community partners explaining the need for investigators to

remain faithful to their methods, follow protocols, be rigorous and systematic in their efforts, and protect human subjects.

After participants provided their own definition of scientific integrity, they were asked for their perspectives on a description of scientific integrity. The description was based upon the characteristics of scientific integrity provided by the National Institute for Environmental Health Sciences in the request for applications to which this project responded. This description included: "proper adherence to responsible research practices. That includes use of honest and verifiable methods of proposing, performing and evaluating research and reporting research results…. [R]esearch conducted with scientific integrity emphasizes adherence to the rules, regulations, guidelines and commonly accepted professional codes or norms that direct collection and interpretation of data from societies, organizations, groups, and individuals" (National Institute of Environmental Health Sciences [NIEHS], 2010). Some participants raised questions about "commonly accepted codes or norms" from the description and who created them: professional or community representatives? Nonetheless, that description was accepted by both sets of CBPR team members. Although the overall concept of scientific integrity was agreed upon, views on the implementation of scientific integrity within CBPR varied widely (Table 4).

Professional Investigators

Four primary themes emerged among the professional investigators' recommended approaches to conducting CBPR with scientific integrity. Two themes related to the concept of flexibility. Most professional investigators suggested that "flexibility" was required to do CBPR and maintain scientific integrity (Table 4). CBPR requires a different flexibility than other research methodologies and approaches because several different partners are making decisions, with both conceptual flexibility and logistical flexibility discussed.

For professional investigators who discussed *conceptual flexibility*, CBPR is different from other research approaches or lab-based research methodologies. Being flexible means understanding what will work within the community and still provide sound scientific results, even if it is not always the most challenging research design. These investigators explained that CBPR requires a different standard for evaluation than more traditional scientific research methods because it must simultaneously satisfy professional and community requirements. CBPR is described as a more "organic process" where all the variables cannot be controlled; the gold standard for CBPR is different from traditional inquiry because CBPR requires that many different stakeholders' opinions be incorporated into the research.

> I believe in scientific integrity…. [That's] one of my biggest beefs with…our field, is that …we still hold CBPR to the standard of…traditional inquiry. I think that our gold standard is traditional inquiry. I've done that. I've been guilty of it… trying to …publish in these high impact journals where you …write something about CBPR and you fit it into that model in order to…change the dynamic. But if we continue to…apply this discourse to a methodology that's far more organic and involves many different stakeholders in that research process, we're shortchanging CBPR. (Professional PI4)

> Well, it works for CBPR, but CBPR is not as pure…because you're dealing with people and behaviors and communities and situations and levels of poverty and education that make it a little difficult…to be as scientifically pure as perhaps the basic science scientists and clinicians would like. And it's not that anything dishonest is being done…it's just simply that you can't get this pure data that's

> based on a test that's run in a[n] analytical machine…it's just not as clear. And it's messy. (Professional PI12)

Participants were able to discuss the many different community and professional variables, stakeholders, and actors involved in CBPR that create entirely different laboratories than for investigators in the bench sciences. They felt that leaving the study site was not as easy as simply leaving the lab, because it was an ever-moving target taking up evenings, weekends, and holidays. The laboratory for CBPR is everyday life, which cannot be simplified and controlled by simply shutting a laboratory door. It requires adapting the research to the needs of the community and finding the best measures possible to ensure scientific integrity while releasing a great portion of control.

Logistical flexibility speaks to the need for aligning study design and protocol with community needs and capabilities, while simultaneously maintaining scientific integrity. Professional participants described the research process as iterative and flexible, because, although changes occur within the project, the research, and the wide variety of stakeholders, this does not mean research integrity should be limited or affected.

> I think there's a level of flexibility…that's just inherent in CBPR because…you don't get to call all the shots. There has to be compromise. But, ultimately … when it comes down to advancing science, I think you would do a disservice to the community if you don't do things in a way that is rigorous and scientific. (Professional PI16)

Several participants echoed that following rules and regulations are necessary, but it is vital to be open to change and flexible to changing protocol in order to maintain balance for all stakeholders. Being open and flexible to changes in recruitment, sample characteristics, and the protocol does not mean having to sacrifice the project or scientific integrity, but requires new ways to approach a question.

> [W]e try to be as flexible as possible…because you can never account for everything that's going to happen in the community. And you may have problems with recruiting who you wanted to, or you have people, like churches or people in the community that decide, "We think it will be best if you had X kids that are sixth graders" or something and your protocol was to have only high schoolers. And then you have to decide. So that may change your protocol. Or you have to do all new informed consent forms because now you have kids that are under 14. ..So I think…CBPR… [needs] to be iterative and flexible and things change, partly as the community learns more about "oh, that's what you're doing," well we think you should do it this way. And they're usually right because they understand the context in which we are working. (Professional PI6)

Logistical flexibility in CBPR scientific integrity also results from a process of growth and discovery with community partners. Flexibility in design and methods can provide different avenues for rigorous inquiry through the development of the relationships with the community partner. Utilizing randomization or being a part of clinical trials can be a part of CBPR but are not necessary. Rather, the development and implementation of particular research methods are based on long term relationships between professional and community investigators which enable exchange of information and ideas, and trust building:

> [W]e were just less rigorous in the beginning, just to build trust…so our first study we did not have a comparison, we had a comparison group but it was a delayed intervention, but then in the middle of that a partner said, "Wait. What is the most rigorous study design we can create so that we can prove to the state that we can do this kind of work?" So it wasn't anything to do with me in the sense that they

> wanted the intervention to be tested in the most rigorous way so that they could get money for that community. (Professional PI22)

The third salient theme that emerged from the professional investigators as a challenge was *Balancing Scientific Integrity with Community Needs*. These investigators struggled between wanting to follow the principles in CBPR and the rules of traditional scientific inquiry. Many argued that following the traditional methods of inquiry can ran counter to the philosophy of CBPR.

> [T]here's the scientific integrity, the confidentiality, the making sure your random sampling is done well, all of that good stuff. But, it also has to have the integrity of what the expectations are of the community… one, that …they are realistic, but then two, if you decide you're going to deliver something that you deliver it….[It requires] that you assure the scientific rigor from design to dissemination…[and], that you ensure community collaboration from design through dissemination…and thirdly that you assure that the outcome is beneficial and sustainable for that community…and that it's measureable. (Professional PI23)

Several participants commented that there was real challenge in balancing between attempting to maintain scientific integrity while also incorporating the community perspective. They explained that it was a process of learning and sharing together in order to try and create a fair and balanced approach incorporating everyone's perspectives.

> To me it's a balance between adapting what you are doing to the community, their needs, without watering things down or altering or changing things as far as how research is done, that what you are doing really has no scientific validity or weight or anything. [Its] the balance between doing what you want to do, whether it's collecting data or… implementing an intervention, and doing it in a way that you incorporate all the input that the community can offer you and they know, this is going to work, this isn't going to work, without sacrificing the integrity of what you are trying to do, the fidelity of a given intervention. [Y]ou have to culturally adapt it and all that stuff but not to the expense of actually doing something that has nothing to do with the original intervention. (Professional PI19)

A fourth theme salient among the professional investigators was the lack of a difference between CBPR and other research methodologies: *CBPR is Traditional Inquiry*. These investigators believed that CBPR must maintain the same rules, regulations, and rigor as laboratory-based science. CBPR was described as being rigorous, with a strong design that considers all variables and is implemented according to the protocol. Doing CBPR means following scientific methods and IRB protocols. One investigator explained scientific integrity in CBPR means, "[t]hat the data is… gathered using legitimate scientific methods and that it is presented in an honest fashion…And it would mean the same thing to me whether it's community-based research or whether it's clinical research or whether it's basic science research…It has the same meaning. It's not anything that's peculiar to community-based research" (Professional PI7). Some participants explained that, while CBPR is attacked for not being rigorous, the fault lies in the professional investigator who did not pursue the appropriate research or relied on doing community action rather than research. One participant stated that the avenue for pursuing scientific rigor is through training the community:

> I don't think it should be different. I think the main difference is that community members don't know how to do it and they don't know how to do in the way we believe is the right way to do it. They don't know all the awful things that have happened in the past, although sometimes they do, and they may not be as worried

about followings rules exactly as we are because they can't get fired for an IRB violation or something. But I think it's up to us to teach them (Professional PI25).

Community Investigators

Discussions of scientific integrity in CBPR by community investigators reflected three themes: trust, benefit for the community and accountability to the community. The Academic-Community Liaisons and Community Investigators did not differ in these themes, and their perspectives are presented together.

Trust was a very salient theme among the community investigators. There were different interpretations of how trust was enacted, but trust was based upon the relationship community investigators had with the professional investigators. Trust was developed through long term relationships, open communication, and having faith in people's word.

A key component of trust for community investigators was the sense that professional investigators sought to protect community members. One participant explained that scientific integrity in CBPR, "involves meeting with the community, getting involved with the community, [and] gain[ing] their trust. They need to feel that you're not going to hurt them" (Community Worker19B). Community investigators explained that they hesitated to participate due to negative previous experiences or community memories of being treated as research subjects or "guinea pigs" in a study rather than as an equal. These investigators maintained that community trust in professional investigators lays the foundation for the partnership to create new kinds of memories.

> If you…have the community buy-in to whatever your research is, if who you have…at the table [is] being serious about the research and the outcomes and they really …[have] the trust in you that you're really there for that and not, as they say, to label them as guinea pigs and that sort of thing… if the credibility, and … communication and …partnership [are]…solidified, then I think the outcome that you get from the researchers and the community [working together] is…like gold. (Community Worker15A)

Trust in science and in not losing the human element were vital elements for community investigators. They explained that trust was associated with clear protocols, adherence to them, and explanation of the protocols. Having transparency in the entire process helped to breed trust among community partners.

> [O]ne of the beauties of CBPR is developing trust…with the community. And I think if you don't have that trust, you can have very skewed results… especially in the kinds of studies that we do in CBPR. So, for example, you could have a project where…if you don't have a community that trusts what you're doing, you might only have certain kinds of people that would want to [participate]…and other people would not…and…that could skew your results… (Community Manager17A)

Trust was also tied to the professional PI. It was imperative that the community trust this person for all aspects of the project, including finances, project design, implementation, results, and the oversight of scientific integrity. Feelings about the professional PIs were deeply personal and possessive, as participants referred to them as "my" or "your" investigator; often the professional PI was the person held ultimately responsible by the community.

> I just think it all goes back to trusting the people…at the top and being able to trust them. Because, at some point you have to trust someone… (Community Investigator7B)

The second salient theme among community investigators was the need for CBPR to provide benefit to the community in order to have scientific integrity. Some community investigators were more experienced and had participated in several CBPR projects, but even those who were new to the field felt strongly that scientific integrity in CBPR means providing *Benefit for the Community*. "If you don't have scientific integrity, then I think you're at great risk of not providing the kinds of services and interventions… that are needed, or maybe resources are diverted into other areas that don't provide the biggest gain …for the buck so to speak" (Community Investigator14A). Benefits for the community could take many forms: financial, health interventions and programs, distributing results back to the community, and community capacity building. Each benefit was tied directly into the research.

> I think there may be two different kinds of integrity. Scientific gets it approved by funding and all that kind of stuff. And maybe there has to be a coming together of the scientific and the non-scientific…With scientific integrity, you just follow the steps of, the scientific method, I guess. As it relates to the neighborhood, you've still got to be respectful and ask them and tell them…what you are trying to do to an extent, at least on layman's terms, and get them to buy into it. And when I say buy into it, accept that that's what we need to do and make sure you share the benefits of the research…and to me that is a significant component of integrity in the process. Sharing the results…of the research with the community…[is]very important. (Community Investigator7B)

Some explained that this concern arose from previous experiences when they felt shortchanged or mined as a data source by professional investigators, which caused them to feel frustration and become aware of what was vital for a community in CBPR. One participant explained, "No, I'm not really frustrated anymore. It's just that I'm aware. You know after a while you realize you're batting your head against a brick wall and nothing is going to change" (Community Investigator15B). From her experiences she believed there were three community benefits that were a part of scientific integrity in CBPR projects, "Including the people from the beginning even prior to you actually applying for the grant… and making sure there's funds allocated for the community and then the findings" (Community Investigator15B).

Some participants explained that it was important to provide a reward, something lasting for the community, besides data, that could make a difference for the population or the community. Suggested benefits included providing a service or training to community members or helping to plan a community garden.

> [T]ry to leave something lasting…not just data….[If] they ask for a little community garden, [then] plant a community garden.…Because you can [then] say, "Oh, well we worked with such and so back in 2006…[and] we planted this garden and we've been getting squash and beans from this garden ever since." It's a small victory. It's a small tangible sign that there's a difference and there was a commitment to seeing a difference…you know, in this particular population. So I think it's just the integrity, the partnerships, doing what you say you're going to do, delivering what you say you're going to deliver, and hopefully leaving the door open for more collaboration, or just, you know, because you have the resources … (Community Worker5a)

Finally, some community partners argued that for CBPR to have scientific integrity there must be *Accountability to the Community*. Many participants directly pointed at the professional investigators and explained that scientific integrity was equal to keeping their promises to the community by being honest, honoring their word, doing what they say they were going to do, and not using the data for other purposes. One respondent said, "To be

honest about the information they're gathering, to assure people that it is only gonna be used for the purpose in which it was gathered, to honor your word. When you say to people, 'Okay, if you participate in this particular research project, we're going to do X, Y and Z,' and you follow up with doing what you said" (Academic-Community Liaison1B).

Transparency was another component of accountability: providing data, results and information to the community in order to empower community members. Many community investigators made it clear that doing good science meant including the community's needs, perspectives, and understandings in the definition of scientific integrity. For these investigators, it was important for professional investigators to stay true to their word and do what they said they would do.

> I feel like there should be some more parts to that definition…[there isn't] once … the word 'community' …in there. So, if this is …scientific integrity and CBPR, [then you have] got to have community in there somewhere. Being accountable to community members…[A]ccountability and transparency…[are] so important when it comes to working together. [S]cientific integrity obviously upholds that same value. So that's really what community members want, you know, like they just want answers, they want to be told the answers. They want to be involved when finding the answers. (Community Investigator23)

Discussion

Scientific integrity is extremely important for professional and community CBPR investigators. Although professional and community investigators share similarities in their interpretations, the differences within and between groups provide insights about CBPR as an approach and the concern about scientific integrity in CBPR projects.

A Continuing Professional Debate over Scientific Integrity in CBPR

The concept of flexibility among the professional investigators does not signify they are flexible in the application of scientific methods. Rather, it means they are willing to bend with the community and make the research design fit what the community can do while upholding scientific integrity. Overall, their relationship with the community is just as vital as scientific integrity, and without their strong relationship with the community the research would not be possible. Power lies with the academic institution in traditional research; and the professional PI determines the research design, direction, and finances for a study (Wallerstein, 1999). However, the participants who identify with conceptual and logistical flexibility turn that idea on its head.

Both conceptual and logistical flexibility may be viewed as logic-in-use and reconstructed logic (Kaplan, 1998). Reconstructed logic refers to the "idealization of scientific practice" or the ideal hypotheses and plans for research that is often found in applications for funding. In contrast, logic-in-use refers to the practical realities of conducting research in everyday life, which often differs from the reconstructed logic (Kaplan, 1998, p.10). Many professional PIs are aware of the differences between the CBPR research that is often proposed and the reality of implementing a community-based participatory research study.

Professional investigators who struggle to balance community needs and desires while implementing rigorous science fit into the theme of "CBPR is a Balance," exemplifying the notion that CBPR is difficult work and embodies a different mentality, time commitment, release of control, and flexibility than traditional scientific research. These participants realize the necessity of working with the schedules and ideas of the community requires melding community needs with their own notions about how to do research.

The drastic differences between the "flexible" professional investigators and "by the book" professional investigators demonstrate the large variability of what is interpreted as scientific integrity in CBPR. While both sides clearly agree that scientific integrity requires remaining faithful to their methods, following protocols, being rigorous and systematic in their efforts, and protecting human subjects, they differ in two key aspects. First, professional investigators who expressed the flexibility theme strongly believe that all variables cannot be controlled or considered in CBPR projects. In contrast, the "by the book" investigators explain that all variables must be considered while doing research. Second, most of the "flexible" professional investigators considered CBPR to be a new paradigm equal to but not measured against traditional inquiry. Contrarily, the "by the book" professional investigators believed CBPR is another form of traditional research. These differences among participants in implementing scientific integrity for CBPR reflect the concerns by the wider professional community about scientific integrity in CBPR (Hueston et al., 2006; Minkler, 2004; Viswanathan, 2004; Wallerstein & Duran, 2006).

Although all of the professional investigators considered the community as a vital part of the definition of CBPR during our interviews, many investigators did not consider the community as part of the definition of scientific integrity. However, there were several professional investigators that believed the community is an integral part of scientific integrity in CBPR. Their interpretation of scientific integrity insisted that community involvement is not only a principle to uphold in CBPR but is an actual part of doing good science.

Upon reflection on their own definition and the definition of scientific integrity offered during the interview, several professional investigators called for a new definition for scientific integrity in CBPR. They understood and agreed with the formal definition of scientific integrity, but felt it lacked the concept of community. They believed that in order for CBPR for maintain scientific integrity there needed to be a new definition of scientific integrity in CBPR. The two professional investigators that called for a new definition of scientific integrity differed in opinion as to what a new definition would be. One believed it should be a less challenging research design to facilitate science and maintain community involvement, while the other viewed it as an operational difference.

Balancing Responsibilities in Scientific Integrity

The three community themes of trust, community benefit, and community accountability present principles for scientific integrity that are different from the professional investigators perspective on scientific integrity in CBPR. While professional investigators interpret scientific integrity within the realm of science and the feasibility of implementation, community investigators took it beyond implementation to bring a humanistic value set to their interpretation of scientific integrity. The elements of trust, benefit, and accountability, while addressing the interpretation of scientific integrity, rationally reflect the basis that forms Israel's nine principles of CBPR (Israel et al. 2005, 1998). Israel's principles of co-learning, collaboration, build onto community resources, and equitable partnerships are all built on trust, community benefit, and accountability. For community members commitment to trust, providing benefit to the community and upholding accountability are just as vital to scientific integrity in CBPR as are following procedure, measurements, and protocols.

Although community investigators were quick to indicate the responsibility of the professional investigators to incorporate different community needs, desires, and considerations into the definition of scientific integrity in CBPR, their discussion lacked including the *community's responsibility* within scientific integrity. While the community wants to be a part of every step of the process, they openly recognized that when it comes to maintaining scientific integrity the job fell to the professional investigators because they are

equipped with the educational backgrounds. In order to maintain a balance of power and partnership, community investigators as well as professional investigators need to provide oversight of the scientific process.

Interpreting Scientific Integrity in CBPR

The professional and community investigators differ meaningfully in their interpretations of scientific integrity for CBPR. The varying perspectives demonstrate their different biases, desires, and needs. The overall concerns about scientific integrity in CBPR among scientists could be satisfied because both professional and community investigators agree upon a general definition for scientific integrity and believe it is absolutely necessary to follow a research protocol (Hueston et al., 2006; Minkler, 2004; Viswanathan, 2004; Wallerstein & Duran, 2006). Nonetheless, both groups of investigators raised questions about “the commonly accepted codes or norms” and who created them. These concerns reflect the greater differences in interpretation of scientific integrity in CBPR between professional and community investigators. In the end, the value set that is reflected in the definition of scientific integrity must be recognized. For the majority of the community investigators, the NIEHS definition of scientific integrity neglected community needs and interests. Professional and community investigators must grapple with the questions of whether it matters who creates the accepted codes or norms, whether scientific integrity in CBPR should include the community perspectives and needs.

If community values are incorporated into a definition of scientific integrity for CBPR, what does that mean if the community is still not providing oversight for all components of the scientific process? For example, they are not involved in data analysis although they are involved in formulating the research design, data collection and dissemination. Often, the professional investigators were labeled as “experts” who have the responsibility to oversee the scientific portion of the project and the community acknowledges that scientific oversight is not their specialty.

If the community desires that their values be represented in the definition of scientific integrity, then do they also need to be responsible for oversight? To have community investigators be able to provide oversight of all scientific processes in design, data collection, analysis and interpretation, they need to be trained and equipped with the necessary skills to fulfill these tasks. Both professional and community investigators called for more training and capacity building for community members directly related to scientific insight and understanding. However, there were also professional and community investigators who firmly believed that the scientific arena was only for the professional.

Limitations

The results of this analysis must be evaluated in light of the study limitations. The nonrandom sample design and qualitative methods may limit drawing wider implications and generalizablity. The structure of funding databases limited contacts to the PIs, who were always professional investigators, could have biased recruitment. However, the projects and participants involved in this study were diverse and provide a good foundation for a broader investigation.

Conclusion

This study is a response to concerns about scientific integrity in CBPR projects (Hueston et al., 2006; Minkler, 2004; Wallerstein & Duran, 2006). These data offer the opportunity to explore the ideas, frustrations, interpretations and needs of professional and community investigators. Salient themes show that professional and community investigators agree that

scientific integrity is essential in research; however, what constitutes as scientific integrity for each group differs (Table 4). For professional investigators, it means being flexible, both conceptually and logistically, in order to come as close as possible to implement the ideal definition of scientific integrity. Community investigators agree that scientific integrity is important but they explain that scientific integrity must include trust, accountability, and overall benefit to the community. This outcome reveals a powerful lack of agreement between professional and community investigators, which can be built into a foundation for greater power-sharing and co-ownership of projects.

Differences between professional and community investigators in their expectations about what constitutes scientific integrity may result in miscommunication and misunderstanding, which creates unclear interaction about project goals and activities. Such misunderstanding can affect the partnership for the current and future projects. This can also affect the quality of data that is collected and the interpretation and translation of study results.

Implications for Scientific Integrity in CBPR - a New Definition

While the professional investigators are grappling to compare CBPR with traditional inquiry and position it as a respectable scientific methodology, the community is simultaneously placing values within the definition scientific integrity in CBPR, a dramatic variation from the definition of scientific integrity in traditional inquiry. The chasm between the interpretations of scientific integrity of community and professional investigators calls for a new definition that is able to embrace the reality for both professional and community investigators. This definition should consider additional professional and community criteria for scientific integrity. The additional professional criterion includes the ability to be flexible in response to community need. The additional community criteria include making the research provide benefit to the community and be accountable to the community.

With a new definition of scientific integrity for CBPR, the key is to incorporate the new definition into common CBPR practice. However, CBPR is currently not measured or evaluated by any set of specific criteria. Currently, the most widely acknowledged set of principles for CBPR practitioners have been identified by Israel and colleagues (1998, 2005). These principles are considered to be a sort of “wish list” with attainment of all nine principles serving as an ideal goal (Green & Mercer, 200; Israel et al., 2003, 2005). Other lists of principles, guidelines, and characteristics have sprung out of this discussion, including the ten “principles of Good Community-Campus Partnerships” by the Community-Campus Partnership with (2006), guidelines and principles for CBPR in 23 items by Green and colleagues (1995), and the critical elements recommend by the AHRQ review (Blumenthal, 2011; Viswanathan, 2004). However, only one of these frameworks mentions scientific rigor as a concern for CBPR evaluation (Viswanathan, 2004).

A new definition for scientific integrity in CBPR must incorporate professional and community values into one definition. This definition should be based on the general definitions from the Panel on Scientific Responsibility (1992, p.4) and the Institute of Medicine (2002, p.4), and add community perspectives: trust, benefit to the community, and accountability to the community. Implementation of the revised definition for scientific integrity in CBPR should make translation of scientific projects a key from a project’s inception. Ideally, building professional and community perspectives into the project design will create a foundation for rigorous science as agreed upon by all CBPR partners.

The sample of 25 projects across nine states reveals the large range of variation and interpretation of scientific integrity within and between professional and community investigators. This study demonstrates the need for clearer, more concrete guidelines for scientific integrity in CBPR. Utilizing CBPR secures large grants for funding professional

and community partners, yet the evaluative process to scrutinize the comparative value of scientific integrity between projects is currently impossible. The practice of CBPR continues to grow and professional and community investigators should strive to provide a better standard for evaluation of scientific integrity in CBPR and of CBPR itself.

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Research highlights

- All investigators agree on the importance of scientific integrity in CBPR.
- Many professional investigators believe scientific integrity requires flexibility.
- Scientific integrity for the community is trust, accountability and benefit.
- This research calls for a new definition of scientific integrity in CBPR.

Table 1

Sample Disposition

Disposition	n	%
No Response	9	18
Declined / Too Busy/Lost to Follow-up	8	16
Ineligible Due to Project Location	2	4
Ineligible Due to Project Stage	2	4
Agreed After Sample Finalized	3	6
Lost Due to Natural Disaster	1	2
Included in Sample	25	50

Table 2

CBPR Project Characteristics

Community Type	Chronic Disease	Environment	Total
Mixed Ethnicity	4	5	9
African-American	5	6	11
Immigrant / Refugee	3	2	5
Total	12	13	25

Table 3

Participant Affiliation and Role

Affiliation and Role	n	%
Academic Staff		
Principal Investigator	25	34
Investigator	5	7
Project Manager	1	1
Academic Community Liaisons	10	14
Community Staff		
Principal Investigator	4	5
Investigator	13	18
Project Manager	4	5
Community Worker	12	16

Table 4

Salient Themes from the Interpretation of Scientific Integrity

Professional Investigators	Community Investigators
Conceptual Flexibility	Trust
Logistical Flexibility	Benefit to the Community
Balancing Scientific Integrity with Community Needs	Accountability to the Community
CBPR is Traditional Inquiry	