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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 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

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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, 2009; 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 et al. (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 et al. (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. 2009; 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.

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

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

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