



Supporting the role of community members employed as research staff: Perspectives of community researchers working in addiction research



Gala True^{a, *}, Leslie B. Alexander^b, Celia B. Fisher^c

^a Associate Professor, Section of General Internal Medicine & Geriatrics, Tulane University School of Medicine, Core Investigator, South Central Mental Illness Research Education and Clinical Center, Southeast Louisiana Veterans Healthcare System, 1555 Poydras St. Room 827, New Orleans LA 70112, United States

^b Mary Hale Chase Chair in the Social Sciences and Social Work Research and Professor, Graduate School of Social Work and Social Research, 300 Airdale Rd, Bryn Mawr, PA 19010, United States

^c Marie Ward Doty University Chair in Ethics, Director, Center for Ethics Education and Professor, Department of Psychology, Fordham University, 441 East Fordham Road, Dealy Hall, Room 117, Bronx, NY 10458, United States

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ABSTRACT

Community researchers are laypersons who conduct research activities in their own communities. In addiction and HIV research, community researchers are valued for their insider status and knowledge. At the same time, their presence on the research team raises concerns about coercion and confidentiality when community researchers and participants know each other personally, and the work of navigating between the worlds of research and community leads to moral distress and burnout for some community researchers. In this paper, we draw upon the concept of 'moral experience' to explore the local moral worlds of community researchers in the context of addiction research. In February and March 2010, we conducted focus groups with 36 community researchers employed on community-based addiction studies in the United States to elicit perspectives on ethical and moral challenges they face in their work and insights on best practices to support their role in research. Community researchers described how their values were realized or thwarted in the context of research, and their strategies for coping with shifting identities and competing priorities. They delineated how their knowledge could be used to inform development of research protocols and help principal investigators build and maintain trust with the community researchers on their teams. Our findings contribute to current understandings of the moral experiences of community members employed in research, and inform policies and practices for the growing field of community-engaged research. Funders, research organizations, and research ethics boards should develop guidelines and standards to ensure studies have key resources in place to support community researchers and ensure quality and integrity of community-engaged work. Investigators who work with community researchers should ensure channels for frontline staff to provide input on research protocols and to create an atmosphere where challenges and concerns can be openly and safely discussed.

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1. Introduction

Community researchers—defined as laypersons employed to conduct research activities in their own communities—play an increasingly important role in health research (Hardy et al., 2016). In this employment model of community-engaged research,

community members (sometimes referred to as *peer recruiters*, *research extenders*, or *community fieldworkers*) are hired to carry out recruitment, enrollment, and data collection activities (Roche et al., 2010). Community researchers (CRs) share life circumstances, social settings, and common experiences with potential research participants. Through past or current personal experiences with the health condition or social problem being studied, CRs bring an emic lens to the research enterprise while sharing key characteristics with research participants. For clinical research conducted in communities where mistrust of research is deeply rooted in

* Corresponding author.

E-mail addresses: Jennifer.True2@va.gov (G. True), lalexand@brynmawr.edu (L.B. Alexander), fisher@fordham.edu (C.B. Fisher).

historical experiences, community leaders have identified inclusion of “individuals who can relate to participants, have similar backgrounds, understand participants’ experiences, and speak their language” on the research team as a necessary step towards building and maintaining trust (Grady et al., 2006: 1998).

In international health research, CRs have been on the frontlines of efforts to address the AIDS pandemic. Through their knowledge of community norms and social connections, community researchers enhance recruitment and retention of participants, and improve uptake of evidence-based therapeutics and practices in clinical and community settings (Simon and Mosavel, 2010; Mosavel et al., 2011; Nostlinger and Loos, 2016). As Molyneux and colleagues have observed, community researchers are essential “cultural brokers between researchers and community members or participants, and have a role in shaping the nature and quality of data” (2009: 310).

In the fields of addiction and HIV research, CRs’ insider status has been key to gaining access and building trust with individuals and communities who face stigma and may engage in illicit activities (Broadhead et al., 1995). CRs bring valuable expertise to the difficult task of identifying and following up with research participants living in precarious or transient circumstances, particularly those who do not access treatment or other services (Griffiths et al., 1993; Madiega et al., 2013). For communities facing discrimination and marginalization, inclusion of CRs as paid research staff can contribute to capacity-building and circulation of scientific knowledge, build collaborations between communities and research organizations, and lead to interventions and policies informed by community expertise (Canadian HIV/AIDS Legal Network, 2005; Aellah and Geissler, 2016; Souleymanov et al., 2016).

As inclusion of community researchers in addiction and HIV research has grown, so has recognition of the potential for ethical conflicts and other challenges. For example, when CRs known for their work on HIV or drug use studies conduct research activities in community spaces and private homes, it increases the risk of exposure and stigmatization for research participants (Madiega et al., 2013; Souleymanov et al., 2016). CRs who work with individuals and communities affected by addiction and serious illness often encounter what has been termed the ‘moral hazard’ of being unable to offer adequate services in the face of great need (Broadhead et al., 1995). Without the means to resolve these moral and ethical conflicts, some CRs experience emotional burnout, while others may deviate from the research protocol in ways that pose a threat to research integrity (True et al., 2011; Richman et al., 2015; Fisher et al., 2013; Molyneux et al., 2013; Kombe et al., 2014).

In this paper, we draw upon the perspectives and experiences of community researchers working in addiction/HIV research to identify key resources necessary to support their involvement in research. By resources we mean support, aid, and assets that can be drawn upon when needed, and actions and strategies which can be adopted in adverse circumstances. Our intended audience includes key stakeholders in community-engaged and community-based research – administrators and reviewers at funding organizations, members of research ethics boards, research investigators and community partners, research staff supervising the work of community researchers, and community researchers themselves. Our goal is to support and strengthen the role of community researchers, and to promote research integrity and responsible conduct of research for studies on which they work.

2. Background

Engagement of community members in research is rooted in consumer-led movements to improve primary health care and

health policy. The origin of CRs in global health research can be traced back to the Alma-Ata Declaration of 1978, which advocated for involvement of community members in public health initiatives because they “know their own situation, are motivated to solve their own problems, and see things from a fresh perspective” (WHO, 1978: 50). In drug use and HIV research, community researchers are part of a continuum of participatory action research. Built upon values first articulated in disability-rights movements such as “Nothing About Us, Without Us,” this approach to drug use and HIV research acknowledges past exploitation of vulnerable populations and calls for meaningful involvement of community members in the research that affects them (Canadian HIV/AIDS Legal Network, 2005; Guta et al., 2014).

Ethnographers conducting fieldwork in communities of drug users have long engaged community members in research; first, as gatekeepers who facilitate access and lend legitimacy to the researcher, and later as peer researchers who conduct interviews and field observations as paid members of the research team. Michael Agar, who documented the lives of urban heroin users through collaboration with key informants, observed the importance of understanding ‘folk models’ of drug use prior to designing or implementing interventions (Agar, 1985). In the 1990s, health researchers began hiring current and former users to facilitate introductions into communities of drug users with HIV, recognizing how these active collaborators could “draw upon sharing rituals and norms of reciprocity” already present in drug user networks (Broadhead et al., 1995: 532). This work required peer researchers to live between two worlds, embracing multiple and fluid identities; some experienced conflicts when their new identity as being ‘in recovery’ and a member of the research team conflicted with their prior identity as an active drug user, but they were required to draw upon that prior identity to achieve success (Broadhead et al., 1995; Power et al., 1995; Blanken and Zuidmulder, 2000). The work of Geissler and Aellah has further explored how research involvement impacts CRs’ identities, as a means to fulfill personal ambitions and associate with scientific gains and knowledge (Geissler, 2011; Aellah and Geissler, 2016).

Recent work by Madiega et al. (2013) tracked how community researchers working on an HIV trial in Western Kenya responded to the need to maintain confidentiality and mistrust of research by pretending to be a friend or distant relative in the presence of non-participants while visiting participants in community and home settings. They observe how the assumption of these alternative identities helped to protect research participants from stigma, but also raised expectations of reciprocity that went beyond standard researcher-participant relationships.

A central tension in the work of CRs concerns how to cope with the structural and social inequalities pervasive in the lives of those affected by addiction and HIV (Broadhead et al., 1995). Several researchers have written about how CRs balanced the daily realities of participants’ hunger and other material needs against their own access to study resources by giving ‘extra’ reimbursements or small personal gifts of their own money (Geissler, 2011; True et al., 2011; Richman et al., 2012; Kingori, 2013; Kamuya et al., 2014). Geissler observes how these responses to the moral obligation to help others have been elided by virtue of their absence from written research protocols and public discussion (Geissler, 2013).

In communities impacted by social and health disparities, participants may view study resources as a means for improving their lives (Fisher, 2009; Aellah and Geissler, 2016) and CRs as gatekeepers to medications, therapeutic interventions, and other scarce resources. In these contexts, CRs who serve ‘dual roles’—that is, conduct research activities but also provide material goods as part of an intervention—face additional challenges to ensuring voluntariness of research participation and balancing power

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