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

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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

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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.

Keywords

community researchers; community engaged research; community based research; research ethics; United States; addiction research; HIV/AIDS research; moral experience

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, 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 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 & Mosavel, 2010; Mosavel et al., 2011; Nostlinger & 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 & 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 (Madiaga, 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., 2012; 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.

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, 1995; Power, 1995; Blanken, 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 & Geissler, 2016).

Recent work by Madiega and colleagues (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 materials 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 & 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 relationships between themselves and research participants (True et al., 2011). These challenges are further exacerbated when CRs become known for providing benefits and access to services and research funding is cut or ceases, making it impossible for them to fulfill community expectations (Madiega et al., 2013).

Fisher and colleagues (2013) conducted a survey of CRs working in addiction research which revealed how community researchers who faced ethical and moral conflicts in an unsupportive organizational climate (i.e. one that does not provide means for addressing job-related stress, sets unrealistic numbers for recruitment goals, or assigns staff to multiple and

potentially conflicting roles) experienced higher levels of moral distress and greater mistrust of research. In addition, many frontline researchers reported behaviors that posed potential threats to research integrity and scientific validity, including discouraging participation in studies they believed would not benefit participants or where they did not trust the investigators, or using their own money to purchase small incentives to enhance recruitment and retention.

The concept of ‘moral experience’ is relevant to examining the experiences and views of community researchers. Hunt and Carnevale define moral experience as “encompassing a person’s sense that values he or she deem important are being realized or thwarted in everyday life... including interpretations of lived encounters... that fall on spectrums of right-wrong, good-bad or just-unjust” (2011: 658). Moral experience acknowledges the impact of CRs’ everyday encounters with participants, community members, supervisors, and institutional representatives such as Institutional Review Board members—and the outcome of these encounters—on their lived experiences and daily tensions encountered while conducting research, rather than overemphasizing major ethical dilemmas which may be rare. Furthermore, the spectrum of right-wrong, good-bad or just-unjust rather than dichotomous or opposing categories (right or wrong, good or bad, just or unjust) more accurately reflects the reality of front-line research, where CRs may respond to a situation by trying to balance the needs of an individual with the research (e.g., coaching a borderline eligible participant on responses to eligibility questions so he or she can have access to study resources, at the potential cost to research integrity). Efforts to balance these needs often leads to moral stress among CRs defined as job burnout, emotional exhaustion, and job cynicism associated with implementing procedures they believe are inadequate or following their own moral conscience in protecting scientific validity or participant welfare (Fisher et al., 2013; Fried & Fisher, 2016).

The present work draws upon the expertise of community researchers working in addiction and HIV research to develop recommendations for supporting their work. Specifically, we sought to understand how the moral experience of CRs-- including the values they deemed most important-- were realized or thwarted by conditions and environments of the studies on which they worked. We also set out to explore how their everyday encounters led them to reflect on strategies and resources for promoting research integrity and responsible conduct of research, with the goal of identifying and describing best practices that may be exported to other research settings.

METHODS

We conducted focus groups with community researchers to explore the continuum of how their values and worldview are reflected and expressed in the context of intersecting social worlds of research work and community. We worked with a Community Advisory Board (CAB) of community researchers, project managers, and research investigators involved in community-based addiction studies that employed community researchers. Study procedures were approved by Institutional Review Boards at Fordham University and Bryn Mawr College.

Participants

We recruited community researchers with recent experience working on community-based addiction studies for focus groups held in Philadelphia, New York City, and Hartford, Connecticut. Individuals were eligible to participate if they conducted face-to-face recruitment, screening, or data collection activities and fulfilled at least one of the following criteria: lived in the same neighborhood where they conducted research activities; had shared experiences in common with research participants (e.g., past addiction); and/or had received services from the sponsoring organization or agency involved in the research studies on which they worked.

Data collection

We convened six focus groups in February and March, 2010. Employing a theoretical sampling strategy, we continued to collect data until no new themes emerged relevant to our main topic of inquiry (Guest et al., 2016). Written informed consent was obtained, and participants completed a background survey. Each participant wore a colored name tag and referred to themselves and others during the discussion by color (e.g., “Mr. Red”).

We designed questions to explore participants’ views on topics relevant to the moral experience of conducting research in their own communities, including questions to stimulate discussion about: challenges of conducting research in vulnerable or under-resourced communities; who benefits most from addiction research; issues that arise around multiple roles of frontline research staff and the need for reciprocity; and views on identity, relationships, and ethical/moral values of different stakeholders in research. We also asked them to share their strategies for dealing with challenges they encountered and suggestions for enhancing human subjects protection and research integrity of studies employing community researchers.

Data analysis

For the purposes of understanding how CRs experienced ethical and moral conflicts in their work, we were interested in their accounts of dilemmas they encountered, what factors they felt contributed to these situations, and how they attempted to resolve these conflicts. Using an inductive thematic approach to data analysis (MacQueen et al., 1998), we developed a codebook through an iterative process of reading, coding, and discussing each transcript as well as our observations and notes from attending the focus groups. Each transcript was coded separately by one of the authors and a trained research assistant to check for intercoder reliability, which was calculated at 97 percent agreement. The authors met regularly to identify overall themes emerging from the data, referencing concepts relevant to moral experience while remaining grounded in the language and concepts of the community researchers. Summaries of themes and exemplar quotations were presented to our CAB for discussion, and their insights were incorporated into the final analysis.

Of the 36 community researchers who participated in our focus groups, there were an equal number of men and women. Twenty were African American, 14 were Hispanic/Latino, and two were non-Hispanic/White. Participants ranged in age from 22–59 (mean=41). Six had

attended some high school or had a GED, 13 had attended some college but not received a degree, 14 had a 2-or 4-year college degree, and 2 had obtained a graduate degree.

By design, all the participants had experience with addiction and/or lived in or near the communities in which they worked. Nearly all reported they had occasional or frequent contact with research participants outside of work—this ranged from sharing friends and frequenting the same social establishments to seeing each other in the grocery store, at church, out in the neighborhood, or on public transportation.

Eleven had between 2–5 years of experience working in addiction research, while an additional 20 had 5 or more years of experience. Nearly all had worked on HIV-related research. They reported conducting research activities such as recruitment, screening for eligibility, conducting informed consent meetings, gathering quantitative and qualitative data collection, and providing risk reduction interventions; this work was done primarily in streets and study participants' homes or other community settings. Over three-quarters received half or all their income from their research work, and greater than two-thirds had health insurance through their research job.

RESULTS

The CRs in our study had been working in research for years, and given the nature of research funding, they were often employed on more than one study at a time, had worked on multiple studies over the years, and had experience working for different investigators and within different organizational contexts. As a result, they provided insights concerning the contrasting moral experience of working in a research climate that supported them in the face of everyday challenges of their work versus one that did not. Reflecting upon their experiences, CRs described how negotiating everyday challenges in research—those not outlined explicitly in protocols or human subjects protections-- revealed the otherwise hidden power dynamics between themselves, their PIs and supervisors, and potential or enrolled research participants. Through analysis of these discussions, we identified five key resources that supported the role of community researchers and positively impacted their moral experience (e.g., led them to feel their values were fully realized in their work environment, rather than being thwarted); CRs in our groups viewed these resources as essential to promoting research integrity. Conversely, community researchers' in our groups described the consequences for research integrity and responsible conduct of research when these resources were absent or inadequate, and how these negative conditions led to the feeling of their values being thwarted in their everyday work. Below, we enumerate each resource theme and illustrate through exemplar quotations how presence or absence of these resources impacted moral experiences of CRs and the consequences for their work. We indicate each respondent by gender, color of the nametag they wore, city, and first or second focus group in each city (e.g., Mr. Red, Philadelphia Group 2).

Resource #1. Attention to and protection of community researchers' physical safety

Community researchers spoke about threats to their physical safety due to the nature of their work, which required them to spend time in private and public spaces where drugs were being sold or consumed. They did not connect these risks to the neighborhoods or

communities in which they lived and worked; rather, danger was framed as one of the occupational risks of outreach work (Broadhead, 1995), and the potential for violence to erupt around drug transactions as an outgrowth of structural determinants such as the criminalization of drugs. Thus, potential exposure to physical danger was viewed by CRs in our study as inherent to the nature of addiction research.

CRs felt strongly that responsibility for protecting their physical safety rested with study investigators and supervisors, and they contrasted the experience of working for supervisors who acknowledged the potential for physical danger in addiction research and provided resources to support safety—such as adequate staffing to allow for working in pairs—with the experience of working on studies where supervisors were unaware of or downplayed safety threats and did not provide essential forms of support to ensure safety. CRs were most critical of supervisors and PIs who emphasized meeting recruitment goals over the safety of research staff, and they contrasted their exposure in the streets with the environments in which most PIs worked; as one CR said:

“There’s a lot of pressure on us to recruit... the investigators get to sit in a nice little office and just wait for all this information to come in... while the folks that are out doing [field] work are working hard, hard, hard.”

(Ms. Yellow, New York City Group 1)

CRs felt their insider knowledge-- such as the ability to detect who was likely to be carrying a weapon or when a drug deal was going on nearby—served as an internal protection against harm. They observed the importance of PIs recognizing and utilizing their expertise by pairing non-community members of the research team with a CR before sending them out to conduct frontline study activities:

“I find it’s always good to have somebody who is well established within the community to bring in somebody who’s not, to introduce them to the community, so they can also build trust. I wouldn’t just drop somebody in Hartford and say ‘go for it.’ It’s better to pair up.”

(Mr. Black, Hartford Group 2)

CRs reflected on how working on well-resourced studies and with supervisors who actively supported their safety in the field led to a positive moral experience, where the CRs’ desire to perform well in their research work was adequately balanced with the need to ensure their personal safety. Even these affirming interactions, however, revealed the uneven power dynamic between CRs and their supervisors or study PIs, where CRs were reliant upon a caring or aware supervisor to acknowledge the realities of field-based addiction research and it was incumbent upon the CR to advocate for his/her personal safety:

“... our supervisors really listen to us and help us when it comes to safety... If I’m going out in the mobile unit, they will bring out male individuals that stay around the van... that presence is good. The second thing is, I don’t go out anywhere without a partner.”

(Ms. Red, New York City Group 2)

The challenge faced by CRs in balancing their work with their physical safety was a prominent theme in every focus group, and highlighted the absence of a standard approach to ensuring the safety of research staff working in the field. CRs described negotiating strategies to protect their safety (and the safety of colleagues) on a study-by-study basis, and the adequacy of protections available to support their safety had a positive or negative impact on their everyday moral experiences of conducting research. CRs understood the advantages they brought to the research because of their knowledge of neighborhoods and people, and pointed out the inherent moral imbalance between their exposure in the field versus the safer spaces in which PIs and supervisors tended to work.

Resource #2: Addressing potential for emotional burnout among community researchers

Community researchers discussed the psychological stressors they experienced in their work, which placed them at higher risk for professional burnout and high turnover. CRs described various strains of living and working in the same community, including the discomfort of running into study participants while seeking health care or other services for themselves, or situations where a research participant expected to be treated as a close friend by the CR when they encountered each other outside the research setting.

In a similar vein, CRs spoke of the necessity of ‘wearing multiple hats’ to be successful at recruiting and retaining study participants. They saw their multiple roles as research worker, neighbor, role model, and someone with knowledge of and access to scarce resources as a source of strength for a study. At the same time, enacting these multiple roles increased the potential for psychological strain. One man described the daily pressure of being asked for cigarettes, money, food, and other items by study participants and feeling he had to provide them to be a good person and continue to be successful at his job. Others discussed how not being able to offer needed services to a research participant led to psychological distress and burnout as evidenced by this exchange between three CR in a Philadelphia focus group:

CR 1: “The turnover rate [for CRs] is immense.”

CR 2: “[It’s] the burn out factor.”

CR 3: “We’re the people that have stuff! Everyone’s asking us for things. I’m never really off [duty]... it’s not a 9–5 job.”

CRs believed principal investigators, institutional review boards, and funders recognized the advantages of including community members on research staff but did not always acknowledge or address the moral stress and moral hazard experienced by CRs conducting research in marginalized and under-resourced communities. Due to their location in the field, CRs faced the everyday pressure of encountering people in need who saw them as gatekeepers to needed resources, which created moral distress when they could not assist people who asked them for help. CRs identified essential resources to ameliorate this distress, including being able to provide food, tokens, or other items such as gloves or socks to research participants who asked them for things:

“Some [CRs] carry their own money to give out for when people ask... but it helps if [the study] provides a little money or free things we can give out.”

(Mr. Purple, Hartford Group 1)

Many CRs experienced moral distress due to conflicting values around the desire to provide service to community members versus the requirements of their research role, and described being caught between the demands of supervisors and moral obligation to their own communities in ways that were highly stressful:

“I came from service providing before I came into research... you want to help, make referrals, make sure these people get what they need. My director was very hard on me... telling me, ‘you are not providing services, you are working in research.’ I went through hell. But then we implemented things like, somebody tests positive, yes, give them a referral.”

(Ms. Purple, New York City Group 1)

CRs also reflected on differences between supervisors and other research staff, who were not constantly faced with the moral hazard of working with distressed populations, and their own situation which offered rare opportunities to ‘exit the field.’ CRs discussed how they had developed strategies for self-care over years of working in research, such as turning off cell phones at night, drawing boundaries for research participants they encountered outside of work, taking ‘mini-vacations’ from frontline research activities, and networking with fellow research staff who faced the same challenges to share tips and develop social support:

“I’d say send [CRs] to conferences, especially other places... I went to a conference and talked to an agency who’s funded by the same people as us and working with the same exact population, and we just compared numbers and what works and doesn’t work. It was so helpful... kind of resolve[d] a little bit of burn-out and also learn things from [each other.]”

(Mr. Brown, Philadelphia Group 2)

CRs observed that many of the solutions to the moral stress and moral hazard they faced in their work required policies, procedures, and budgeting embedded in the research protocol. They noted that, in most cases, the power to implement these changes lay in the hand of study PIs, IRBs, and funding agencies, with CRs left to navigate complicated relationships between the research and community worlds largely on their own. In addition, their discussions revealed how their unpaid emotional labor contributed to the success of the research they worked on, but went largely unacknowledged by those who relied on them to perform this work.

Resource #3: Protecting against potential threats to voluntariness and confidentiality

Community researchers experienced moral distress in the context of their interactions with participants who might be ‘high’ during recruitment and informed consent, and felt their personal experience with addiction was a resource in recognizing when this problem arose during recruitment. They spoke of troubling experiences working on studies where the emphasis was on reaching recruitment goals over ensuring a participant was capable of informed consent, and stressed the importance of a good relationship with a supervisor or study PI who deferred to the CR’s judgment. As one CR pointed out:

“That [situation] is where you’re supposed to have a good connection with your supervisor... to let them know... right now, this person can’t participate.”

(Mr. Red, Philadelphia Group 2)

CRs outlined how their insider status enabled them to connect with research participants but also posed a potential threat to confidentiality. For example, CRs who worked on HIV studies in one city said the mobile van they worked out of was known as ‘the HIV van,’ and thus anyone coming up to the van might be presumed to be HIV positive by neighbors who saw them. CRs who worked on HIV-related studies in a different city talked about the importance of having information about multiple studies and services available so they would not be associated with only one type of research:

“We usually have multiple studies going on so it’s not pinpointed to just one study [topic]. So we have multiple studies going on, I ask you a few questions, and if you’re eligible for any of them you can come in... so we don’t just say it’s an HIV study.”

(Mr. Orange, Philadelphia Group 2)

Community researchers observed how going into people’s homes and building relationships with them facilitated data collection but also created potential confusion about the nature and extent of the relationship that had consequences for human subjects protection. CRs expressed concern that the trust they engendered as a familiar face in the community might lead to a potential participant ignoring or not listening fully to the risks of the research as presented during the informed consent process. Some CRs said they dealt with this by going through informed consent slowly and deliberately even when a potential participant urged them to rush or skip the process. CRs also spoke of how their dual roles as service providers and researchers had the potential to compromise informed consent procedures when a potential participant perceived that receiving drug counseling or access to other resources was dependent upon being eligible for or participating in a research study:

“Whether you want to or not, you end up building a relationship with these people. I’ve had people calling me [late] at night... because I tell people, when I present myself, ‘I’m in your home and you’re divulging all this information’... so while we’re there, yeah, we’re friends, and that’s why you’re telling me all this information.”

(Ms. Orange, New York City Group 1)

They suggested it was important for PIs and supervisors to account for these challenges when designing research protocols to ensure adequate separation of research and service roles, and to provide training and ongoing support to help research staff develop and maintain skills to navigate these challenges during the informed consent process.

“Sometimes we take on dual roles, but usually there is an order of questions. So you might ask the risk questions first, and then do the counseling part so they don’t feel they have to meet your expectations when you ask the risk questions.”

(Ms. Red, Philadelphia Group 1)

Thus, CRs experienced moral stress around the recognition that their multiple and shifting identities served as an asset in conducting research in marginalized communities, but, if not

properly managed, posed threats to responsible conduct of research in those same communities.

Resource #4: Incorporating CRs' knowledge to develop research protocols that reflect realities 'on the ground'

Community researchers identified areas where study protocols failed to fit with realities they encountered 'on the ground' in their research work, resulting in threats to research integrity. For example, CRs discussed the challenges of working on a study where the inclusion criteria did not accurately reflect characteristics of the research population, making it difficult to find eligible participants and, in some cases, leading to enrollment of ineligible persons either through recruiter error or because potential participants learned to adapt their responses to ensure being enrolled even when they weren't eligible:

“A lot of times, what would make somebody eligible for a study is so strict that you cancel out so many people trying to find the small amount of folks that don't really exist. People make themselves fall into the categories that researchers are looking for, but they're not necessarily truly representative of that population. I think the word gets out on the street, what [researchers] are looking for and [participants] mold themselves to be what you're looking for.”

(Ms. Yellow, New York City Group 1)

CRs spoke of the challenge of daily encounters with participants who viewed research studies as a means to access medication and treatment services. While they expressed frustration at social and structural inequalities in their communities, they also framed these encounters as a challenge to maintaining data integrity:

There are groups of people that just go from place to place to place just filling out stuff. Professional research participants. One day you're taking this drug and another day you're taking that drug.”

(Mr. Green, New York City Group 2)

CRs expressed frustration over working for PIs and supervisors who hired them because of their knowledge of and experience with the communities being researched, but did not draw on the expertise of the CR to develop screening processes that could protect against enrolling ineligible participants. A related topic emerged around the problem of investigators (or research institutions) concentrating all their recruitment activities in the same handful of neighborhoods and communities, leading to studies that had excessive crossover among participants. One CR observed:

“I've been doing [this] for 10 years... And a lot of times, I see the same faces. We are getting the same old people”

(Ms. Brown, Philadelphia Group 2)

CRs talked about strategies they developed to avoid enrolling ineligible participants or enrolling the same participants in different studies over time. These included using their own knowledge of and experiences with the community or the topic being researched to detect who might be giving false responses; as one CR said:

“I know when someone is BS-ing me... that person is not what we’re looking for...”

(Ms. Yellow, New York City Group 1).

Other CRs spoke of using their insider knowledge of neighborhoods to recruit in new locations. Some CRs worked on studies where they did initial screening interviews on the streets, but other research staff conducted additional screening on the research site; these CRs expressed confidence that additional screening questions would ‘weed out’ ineligible people.

The CRs in our groups spoke of working for investigators who were unaware of or ignored how aspects of the protocol—specifically, a high burden of questionnaires or excessive paperwork—could result in threats to research integrity. For example, as when CRs made data collection or entry mistakes while dealing with a high volume of forms, or when participants gave inaccurate responses to speed through long surveys. In addition, CRs observed how excessive data collection instruments could lead some CRs to ‘cut corners’ to avoid falling behind on data collection, another threat to research integrity.

Many community researchers perceived the integrity of addiction studies as impeded by investigators and IRB members who lacked knowledge of real-world drug use. CRs in one group traded stories about researchers who learned everything they knew about drug use and addiction from reading journal articles. In another group, a CR talked about how lack of practical knowledge about heroin use resulted in failure to recruit adequate participants when the PI and IRB failed to detect deficiencies in the study protocol or remedy them in a timely manner:

“Well, I’ve had direct contact with the IRB and I think one of the most annoying things is when... you wanna actually end up recruiting a person [who used 4 bags of heroin in the past week as opposed to 5], but you have to make sure you pass that with the IRB. But by the time that whole thing [a modification approval] goes through, that person is gone.”

(Ms. Pink, New York City Group 1)

Community researchers saw themselves as key resources for funders and investigators in identifying challenges early on and mitigating negative impacts on the research. They recognized the pressures to obtain funding that investigators face, and suspected that some PIs painted an unrealistic picture or were overly ambitious in proposals to be competitive for funding. CRs pointed out that given their knowledge of research, the communities being researched, and experiences on the front lines of recruitment and data collection, they were uniquely positioned to advise PIs from the design of research trials all the way through to data collection. Regarding the issue of research participants who gave false responses to be eligible for study participations, one CR cited a positive example of a PI who incorporated feedback from frontline research staff to address the problem early:

“We had [a] question at the [end of each interview] on my last study. They asked us ‘Do you feel that this [data] was reliable, unreliable, or inconsistent?’ I think that was one of the best things they did. That one question is very important.”

(Mr. Red, New York City Group 2)

CRs viewed their knowledge and experiences as a vital resource to PIs; when PIs and supervisors sought out and heeded their feedback, CRs felt this process strengthened the integrity of the research and their value to the research was recognized.

Resource #5: Efforts to build and maintain trust between academic and community researchers

Many CRs identified with mistrust of research and researchers that has been well-documented in some minority or underserved communities, and they referenced historical mistrust of research in their communities based on past exploitation by researchers. Most CRs perceived drug addiction studies as problematic from a social justice perspective. A source of moral distress centered around CRs' views that many addiction research studies were conducted with poor urban drug users because they were easier to recruit compared with middle class suburban drug users or would be willing participants because they had no other way to access services and resources. CRs were frustrated with what they viewed as an overemphasis in research on risky behaviors as occurring only among urban and poor minority communities:

“[There is] the tendency to associate drug addiction with underserved and poverty. There’s a lot of working people-- rich people-- that use drugs and are addicted. But when we’re doing research, what do we look for? The African-Americans, the lowest... They [researchers] go to homeless shelters, they go to drug programs.”

(Mr. Red, Hartford Group 1)

Furthermore, CRs felt that benefits and burdens of research were not distributed fairly; that those populations who bore the burdens of research (poor, urban, minority drug users) were less likely to benefit from research findings compared with others (suburban or wealthier addicts, research investigators, pharmaceutical companies):

“I think, in terms of benefits, first [the research] will benefit the companies, the pharmaceutical companies, because they can get a profit. Then the researchers will get grants, and somewhere, questionably, the community [will benefit] at some point.”

(Mr. Red, New York City Group 1)

CRs noted that, when potential participants in the community were aware they were being ‘used’ by researchers, this led to community members figuring out ways to ‘use’ the researchers in return by faking eligibility to gain access to study compensation and other benefits. Some CRs who doubted the integrity of a study or investigator, or did not believe the study would eventually benefit the communities in which they worked, said it lessened their motivation to recruit for that study. Conversely, CRs who had faith in the motivations of the PIs for whom or strongly believed the research they were involved in would eventually benefit the community expressed pride in their research work and a desire to see the research conclude successfully:

“We collected a lot of the data for [a national needle exchange program] to become local, so that’s one of the things I’m really proud of doing in the field.”

(Ms. Purple, New York City Group 1)

CRs said they could only be successful in their work if they were able to bridge the gaps in knowledge, familiarity, and trust between the communities being researched and the researchers for whom they worked. They stressed the importance of being very knowledgeable about the study so they could impart confidence to research participants who expressed mistrust:

“I will learn everything about the research... because you cannot project something that you don't know. If they see that you know what you're talking about, the tendency is to trust you and be honest with you.”

(Ms. Yellow, Hartford Group 1)

CRs spoke of positive experiences with investigators who acknowledged the challenges of front-line recruitment and data collection in addiction research, and took steps to address these challenges:

“I think our particular PI, he recognizes that there's distrust in the community, and he's one of the first people to say 'these are some of the things that have happened, that our institution has done or that research has done that gives people a bad feeling about it. He's one of the first people to diffuse that from the beginning, and I think just acknowledging that and then listening to people's concerns helps with that.”

(Ms. Orange, Philadelphia Group 1)

In summary, CRs who worked for investigators whose behaviors engendered trust were better able to function in their research role and less likely to experience core elements of moral distress such as emotional burnout and job cynicism. Furthermore, CRs wanted to avoid working on studies that risked further exploitation of already stigmatized communities by commodifying their bodies and suffering for the benefit of researchers, pharmaceutical companies, and more privileged addicts.

Discussion

In this paper, we draw from the insights of community researchers to identify the most pressing ethical and practical challenges they face in their work and describe potential resources and best practices for addressing these challenges. This work builds on current understandings of the moral experiences of community members employed on research teams, and how their values—which are often shared with the communities being researched—are realized or thwarted by factors such as the extent to which researchers understand realities of the local worlds in which research is being conducted.

Nearly all the CRs in our focus groups had personal experience with addiction or other health issues (e.g., HIV positive status); this shared experience between the research worker and members of the researched community has sometimes been referred to in the literature as ‘cultural proximity’ (Simon & Mosavel, 2010; Mosavel et al., 2011). In addition, most CRs lived in or were familiar with the neighborhoods and social hangouts of potential research participants, and all conducted most of their work in the neighborhoods and homes

of research participants; this has been referred to as ‘physical proximity’ (Richman et al., 2012). Many CRs saw their ability to understand and navigate between the research and community worlds as a strength that traditional research assistants and PIs did not necessarily possess. They believed their cultural and physical proximity to research participants, and their ability to shift between research and community identities, were major contributors to their success as recruiters and data gatherers. They also saw these proximities and shifting subjectivities as a ‘double-edged sword’ with possible negative impacts on aspects of human subjects protection and their own wellbeing. CRs suggested PIs could support them and ease these pressures by giving CRs sufficient information about the study to retain community trust, acknowledging pressures of fulfilling dual roles (researcher and service provider), building resources or referrals for community members (regardless of whether they ended up as a research participant) into protocols, and providing CRs with opportunities to connect with other CRs through attendance at conferences and continuing education. Others have suggested additional practices, such as reviewing names of potential participants to ensure CRs are not enrolling subjects they know personally and weekly debriefing meetings to address emotional stress experienced by CRs (Simon & Mosavel, 2010).

In the field of international research, greater attention has been paid to challenges raised when investigators and their teams engage in research activities in extremely under-resourced countries and communities. These include relationship dilemmas and other stressors on fieldworkers, who are often seen as ‘gatekeepers’ to resources or resented for their paid research positions and face raised expectations from study participants and local communities (Molyneux et al., 2009; Kamuya et al., 2013; Kamuya et al., 2014). Suggestions for supporting frontline research workers and strengthening human subjects protection include providing customized ethics training that draws upon past challenges of fieldworkers working in similar contexts to incorporate local examples, role-play, and immediate feedback (Kamuya et al., 2014; Kostick et al., 2014). Given the particularities of each study and the evolving nature of dilemmas encountered in the field, such training should be continuous and include regular debriefing sessions and observations in the field by supervisors to keep them apprised of the conditions in which CRs are conducting research activities.

Madiega and colleagues (2013) and Geissler (2011; 2013) have written about the strategies CRs employ in an effort to resolve daily moral and ethical dilemmas in their work, including adopting alternative identities to avoid disclosing a participant’s HIV status and sharing resources (their own or study-related) with community members and participants in need. As Geissler notes, these actions have the potential to violate regulations related to human subjects protection but are not part of official discussions about ethics of community engaged research at the local or policy level. CRs in our study reflected on these same issues, and noted how their values (e.g., being able to provide some material benefit to participants, having an outlet to discuss concerns about data integrity) were supported when PIs and supervisors created opportunities for open and safe dialogue and acted upon CRs’ input. They also noted the injustice of expecting CRs to provide material benefits to participants and potential participants rather than building these small gifts into the research budget. Thus, it is important to create an environment within a study team or research

organization where CRs can discuss their perceptions of how aspects of how research is organized fall along the spectrum of just-unjust, and disclose the daily dilemmas and actions they have taken to resolve these dilemmas (even actions that violate the research protocol) without fear of negative repercussions.

Slightly more than half of our focus group participants had five years or more of research experience. During focus group discussions, some CRs reported positive experiences with PIs and supervisors—such as being asked for input on research protocols and attending weekly meetings to discuss recruitment challenges—which made them feel more invested in the research and their long-term relationships with PIs. This echoes previous work which has identified associations between supportive organizational climates, greater commitment to research, and lower levels of moral stress among frontline research workers. CRs in our focus groups observed that respect and consideration from the study PI and other supervisors not only enhanced research integrity, but also protected them from burnout. Speaking of CR colleagues who worked for investigators whom they saw as less conscientious, one CR observed they tended to experience job burnout and leave research after about 3 years. This seems like another route by which research integrity is threatened, since CRs in our groups cited the number of years they had been working in research as protective in terms of their understanding of the protocol, how to avoid cutting corners, and ability to build community rapport to recruit participants while avoiding dangerous situations.

There are limitations to our study. Our sample was not randomly selected but self-referred in response to a study recruitment flier. We used focus groups to engage CRs in discussions about the challenges they faced and resources and strategies they used to address these challenges; individual interviews may have yielded different views and experiences, as would observational or ethnographic methods.

All CRs in our focus groups came from an addiction research background; experiences and views of CRs engaged in other types of research may differ. However, this is mitigated by the fact that many CRs who participated in our study had experiences working on a variety of non-addiction studies as well and most had worked in HIV/AIDS research. Many of the insights offered by participants in our focus groups echo the experiences of CRs working in global health research in areas other than addiction research.

The congruence between experiences and views of CRs in our study and those working in international settings suggests that key aspects of the moral experience of community members conducting research in their own communities stems less from the particularities of location or context and more from the ways in which the research enterprise is organized. Our findings expand on previous work by examining how CRs' are left to navigate everyday ethical challenges in their work, and are in most cases dependent upon the awareness and integrity of PIs and supervisors to support or thwart their efforts to resolve experiences of moral hazard and moral distress.

Our findings provide important recommendations for strengthening the role of community researchers that can be adopted by key stakeholders in community-engaged health research including funders, principal investigators and supervisory research staff, institutional review

boards, and other CRs. Community researchers in our study suggested that PIs, IRB members, and personnel at funding organizations (e.g., program officers) needed to get out into the field more often to fully grasp the demands of conducting community-based research and inform development of funding mechanisms, research protocols, and ethical review processes that were more realistic and reflective of realities on the ground. CRs emphasized the central role played by an investigator's level of knowledge about the 'researched' community in facilitating or impeding the work of CRs and, ultimately, the integrity of the research itself. As community-engaged research become more common, it is important to develop training and guidelines for investigators who wish to employ community researchers. The CRs in our study pointed out how working for PIs who lacked knowledge about the realities of the daily work of community based research led to recruitment challenges and emotional burnout, pointing to the need for more rigorous review by funders and research ethics boards (REBs) of research proposals and protocols. Finally, CRs suggested that REBs themselves, whose members are more familiar with clinical research, would benefit from additional training about field-based and community-engaged research.

Our findings, which draw directly from the expertise and experiences of community researchers, may help investigators and others who already employ CRs examine their current practices to identify strengths as well as opportunities to implement new policies, training, and procedures, while investigators who plan to include CRs on their research team may use this work to inform early research design and implementation. Above all, creating space for reflexive and ongoing discourse on the challenges and advantages of conducting research in one's own community—including acknowledgement of the tensions created by daily encounters and spectrum of ways in which such tensions may be resolved—is essential to supporting the work of community researchers and their roles on research teams, as well as enhancing research integrity of the studies on which they work.

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Research Highlights

- Provides ethical recommendations for stakeholders in community engaged research
- Contributes insights from community members employed in addiction research
- Identifies resources for supporting research staff who conduct field based work