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Community Researchers Conducting Health Disparities Research: Ethical and other insights from fieldwork journaling

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Abstract

Lay persons who are trained to conduct research in their own communities form an essential part of many research projects. However, the effects of conducting research in their own communities have not been adequately explored. This paper examines the experiences, perceptions, and challenges faced by a group of community researchers during their involvement in a research project that examined if, and how, the relationships between mothers and their adolescent daughters could be harnessed to develop a daughter-initiated cervical cancer intervention. Seven community researchers interviewed 157 mother-daughter pairs in Cape Town, South Africa. We examine the use of journaling as a tool to document the experiences of community researchers, and we consider how journaling may help the community-based researcher grapple with the research process, and, more broadly, what such journal content illustrates with respect to the nature and challenges of community-engaged health research. An analysis of the content of the journals provides a strong indication of how personal and intimate the research process can be for community researchers by virtue of the background that they bring into the process as well as the additional weight of the research process itself. The complexities of navigating dual and somewhat oppositional roles – the role of impartial scientist or researcher and the role of invested community person – has been both underestimated and insufficiently researched.

Keywords

South Africa; community researchers; challenges; journals; fieldwork; community-engaged research; Community based participatory research (CBPR); peer researchers; ethics

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Introduction

A growing body of literature discusses the impact of research upon researchers and investigators. However, such studies are confined to the primary investigator and not necessarily the lay person as researcher. Often, research can be emotionally taxing, causing psychological strain on those conducting it (Beale, Cole, Hillege, McMaster, & Nagy, 2003; Kidd & Finlayson, 2006; Lalor, Begley, & Devane, 2006; Malacrida, 2007). Researchers, especially those who conduct qualitative research can become emotionally involved in their work and may, on occasion, experience anger, frustration, shock, and distress in reaction to information collected through their research (Beale, et al., 2003). These feelings are often augmented when research involves spending time with people who have difficult life experiences or are in some way disadvantaged or marginalized (Banks-Wallace, 2008). Furthermore, emotional fallout among researchers participating in demanding team research has been documented (Lalor, et al., 2006; Malacrida, 2007).

With the increased interest in involving lay persons in various aspects of research (Minkler, Garcia, Williams, LoPresti, & Lilly, 2010; Suarez-Balcazar & Kinney, 2006), especially health disparities and community engaged research, it is particularly important that researchers identify challenges that lay persons may experience when they step into the additional role of community researcher. Furthermore, it is likely that the community researcher may have personally experienced some of the same predicaments, dilemmas or concerns about which they are collecting data (Banks-Wallace, 2008; Kanuha, 2000). In this paper, we use the term “community researcher” to describe lay persons from the local community who had no prior experience with research and received training to conduct semi-structured interviews. However, other terms used to describe this role include peer researcher (Flicker, Roche, & Guta, 2010).

Community based participatory research (CBPR) and various other community engaged research projects incorporate training community members as research team members. Sharing attributes can blur the line between researcher and research participant (Kanuha, 2000). Exposure to the lives and struggles of those being researched can take on personal meaning and become emotionally draining for all researchers, but particularly for community members taking on the role of researcher. Researchers who can deeply identify with the research participants may have a harder time keeping an emotional distance; especially, when the possibility exists that the researchers share similar experiences and life struggles with those they interview (Banks-Wallace, 2008). While some scholars have argued that this emotional distance is a barrier to conducting more engaged and compassionate science (Bondi, 2003; Guillemin & Heggen, 2009), the reality remains that many funding agencies and centers of scientific research adhere to scientific positivism and objectivity, and are adverse to subjective and reflexive research to an extent that discourages many researchers from experimenting with these alternative forms of scientific engagement. Hence, the broader context of how scientific research is typically understood and funded contributes to the common practice of placing researchers in situations where they feel obligated to keep their emotional distance from their research topics and participants. The theoretical framework used in this research is one that attempts to blend strong empirical science with a social justice and empowerment paradigm (Small, 1995). Research is not a value-neutral exercise, and a high level of engagement can facilitate richer data with greater social utility (Minkler, 2000).

The objective of this paper is to explore the effect of conducting research on community researchers in the context of an international health research study, in which, community members were recruited, trained, and asked to participate in a variety of research activities. The effects of research that emphasizes a scientific objectivity and neutrality, on the one

hand, while exposing community researchers to the highly subjective world of community life and suffering, on the other, have not received adequate focus. To address this gap, this paper examines the role of journaling among researchers who are from, and identifies with, the community that is being invited to participate in international research. It considers how journaling may help the community-based researcher grapple with the research process and, more broadly, what such journal content illustrates with respect to the nature and challenges of community-engaged health research. Finally, this paper considers some of the ethical issues related to the process of utilizing journals generated by research teams.

Methods

Design

The cervical cancer prevention study that provides the context for this paper was an exploratory behavioral study conducted between 2006 and 2008 with adolescent girls and adult women at risk for cervical cancer in a resource-poor community outside Cape Town, South Africa. The study examined the feasibility of using adolescent daughters to provide their mothers with cancer screening advice. The survey explored the mother-daughter relationship as well as cancer beliefs and attitudes. We identified and trained seven lay persons to conduct semi-structured interviews with 157 mother and daughter pairs. We used a community-based participatory framework (Mosavel, Simon, & Van Stade, 2006; Mosavel, Simon, Van Stade, & Buchbinder, 2005; Simon & Mosavel, 2008, 2010).

The community

Masidaal is a peri-urban community that lies on the outskirts of Cape Town, South Africa and has a population of more than 60,000 residents. It is a poor community typified by extremely high unemployment (>45%) and, consequently, very high crime and violence rates. Per the IRB requirements, all the names of participants and the community have been changed.

Journaling

Journaling has been used in several different contexts as a method of support with the goal of allowing for self-reflection, potentially leading to awareness and growth (Lalor, et al., 2006; Malacrida, 2007). The benefits of journaling, including effective self-reflection, emotional release, and increased awareness, have been well documented (Keeling, 2006; Pennebaker, 1997). Additionally, journaling can be used as a therapeutic process when dealing with emotional experiences or stressful events (Ullrich & Lutgendorf, 2002), as well as to improve psychological well-being (Smyth, 1998).

When used as a reflective practice, journaling can be empowering (Johns, 2002; Tillman, 2003). For example, journaling is used in nursing as a way to enhance self-reflection, encourage growth, and discover meaning (Blake, 2005). Journaling can be a way for an individual to find and express his or her own voice (Lauterbach & Hentz, 2005). In this manner, individuals can assert their beliefs, affirm “the powerful self,” and empower themselves to recognize and validate feelings and experiences (Johns, 2002). Furthermore, reflective journaling can also be an invaluable tool that can assist with educational outcomes (Clark, 2009 ; Langley & Brown, 2010).

Journaling has been used as a tool for reflection and coping with challenges in the conduct of qualitative research. However, this paper argues that the use of journaling needs to be expanded to include community-based research and non-qualitative data collection methods used in low-resource settings as well as research in which those who collect the data may have a strong connection to the community or the content area. Moreover, journaling may be

particularly useful in international research where additional practical, cultural, and psychosocial issues come into play.

Community researcher recruitment

Community members were eligible if they were female, lived in Masidaal, had at least a high school diploma, and spoke English as well as either Xhosa or Afrikaans. We aimed to recruit some community researchers who were in their early twenties, with whom the adolescent participants would be able to relate to. More generally, we were interested in women who were at least somewhat engaged in their community through volunteer activities.

The seven community researchers were recruited by word of mouth. Each person who expressed interest was interviewed extensively, given information about the project, and provided a chance to ask questions in order to promote mutual compatibility and transparency. Community researchers were offered an hourly rate comparable to what research institutions in South Africa typically pay for similar community-based research roles. Nine women were interviewed and five new researchers were selected. Two were retained from a previous project which made for a total of seven researchers.

Training

We provided two weeks of extensive training on various aspects of the research process, including the informed consent process, challenges that they may encounter during fieldwork, and interviewing techniques. Community researchers were involved in instrument development as well as the piloting of the instrument, which allowed valuable opportunity for further hands on training. The PIs provided the two week training, and one of the PIs was present during the pilot testing phase. Once the project was underway, weekly group, as well as individual, training was provided, primarily, by the research coordinator.

Journaling Process

Community researchers reported that during the semi-structured interviews, mothers and daughters seemed to be sharing very intimate details about their lives which greatly affected them (Simon & Mosavel, 2010). In response to their difficulty dealing with the intensity of the emotional and social context of those interviewed, the research team decided on two approaches. First, researchers were provided with notebooks in which they were encouraged to document their experiences during the research process. Other than suggesting to community researchers that they write about their experiences collecting data for the project, minimal instructions were given with regard to journaling. It was explained that this process might help them cope with some of their research experiences. Secondly, a local colleague and psychologist (RA) was asked to join the group and facilitate regular debriefing meetings with the community researchers. The initial goal for bringing in the psychologist was to provide both the ongoing research training as well as emotional support. However, many of these sessions were often more a forum for the group to talk about their difficulties, much of which they wrote about in the journals. All community researchers attended the debriefing sessions with the psychologist. Furthermore, to address safety concerns, the community researchers were advised to interview in pairs or to take a “protector” with them, and to avoid high risk community situations. One person, occasionally, used a “protector” and we provided a stipend. The researchers were given clear instructions to terminate the interview should any safety concerns emerge.

Consent

We received approval from the Department of Education in the Western Cape, South Africa and from our institutional review board in the U.S. to conduct the research study on cervical cancer. A few months after the official start of the research, we applied for, and received, approval for an amendment to the original study to include evaluation, analysis, and publication of the community researchers' experiences, including their journal entries (IRB amendment #00001895).

Prior to providing the notebooks, we obtained written informed consent from all the community researchers. The consent process informed them that the investigators would be collecting their journaling notes to better understand their challenges during the research implementation process. They were told that their names would not be used and that the journals would be collected at the end of the study. When we collected the journals, some of the community researchers expressed that they would prefer their real names used in any publications emanating from their journal entries because they wanted the "world to know about them and help their community." Our IRB approval did not, however, allow for this contingency; hence, all community researcher names and other clearly identifying information have been removed from, or replaced in, the data presented in this paper.

Upon completing a full draft of this manuscript, we procured additional IRB approval to contact the community researchers to corroborate their interest and willingness in seeing this work published, and to share and seek input from them regarding the manuscript draft. We were able to meet with all of the community researchers in person. Feedback on the manuscript included comments such as feeling validated, happy that their voices are heard, and glad that their community's story is being told.

Data analysis

Six journals were analyzed (see Table 1). The seventh community researcher said it was too hard for her to write in the journal because too many things were happening in her life at that time to devote time to writing the journal entries. Five of the journals were written in English, while the other one was partly written in Afrikaans and English. The six journal entries were manually reviewed by two coders who speak both languages.

We used a grounded theory approach (Patton, 2002) and developed inductive codes based on the review of each journal. We identified common codes from each of the six journals. The two coders compared and discussed the identified codes and reached agreement on the common themes. Inter-rater reliability was high (98%) and there were only differences about how best to frame the various themes. What follows are the results of this inductive analysis.

Results

Although each journal was distinct and individual, there was considerable overlap in the content of all six women's journals, including the process of becoming a community researcher and its value in providing much-needed income, mastering the research process, how the research affected them on a personal level, how the research increased their sense of community awareness, and how being engaged in this process was a source of self-empowerment. It is important to note that the themes presented themselves in their journals in, more or less, the above order, illustrating how the meaningfulness of their research involvement evolved over time. Below, we expand on these overlapping themes.

At first, it was about the money.... “sharing bread.”

In poor communities, where unemployment is rife, it is not unusual for community members to volunteer their services or agree to participate in research in the hope that job opportunities would arise from this participation. Four of the six community researchers' initial journal entries confirm the view that their participation was motivated by paid employment possibilities. The scarcity of jobs in the region and their inability to secure employment elsewhere were the primary motivators for them to agree to become community researchers. For example, Marel had a husband, son and a daughter and needed money to better her family's financial situation. She was introduced by a friend on the project who wanted her to share in her good fortune of earning money. Marel described her introduction to the research project as:

“This certain friend on the project came up to me and told me that she has two breads and that she wants to share with me - actually she want[ed] to give one of her ‘two’ breads to me.”

Kaya was working as a part-time waitress and had to travel far to her place of employment. She was desperate to find more local employment since she did not have any transportation. She was new to Cape Town, having relocated to the city from a more rural area in South Africa, and needed to find a job, so that she could help support her mother in raising the family. According to her:

“I was just thinking about money because I was so desperate....When I come here in Cape Town, I was desperately looking for a job, so that I can help my mother who's responsible for everything - who has to pay the school fees, buy food, do everything, so that she cannot feel that pain that she has been through.”

Like Kaya, Myrtle was originally from another province in the Eastern region of South Africa, but had been living in the Western Cape at the time of the project. She used to own a business, but she lost everything. She was desperate for a job when this opportunity came along and was working part-time as a domestic worker to support herself and her son. Similarly, Jeanette saw the project as an opportunity to earn money and to provide for her family.

While money was a more immediate motivator for the women, there were secondary reasons for pursuing the research opportunity. None of the women had worked as researchers before and were impressed that they were chosen to do a job they felt was outside their realm of work possibilities. Most, if not all, of the community researchers regarded the data collection as challenging before they had even started. Four of them said they saw this as an opportunity to improve their skills and competencies. In particular, Jeanette, Kaya, Myrtle and Marel seemed to lack confidence in their abilities to conduct the research. Myrtle expressed that her insecurity stemmed from having been surrounded by people who made her believe that she would not amount to much. Marel saw this work opportunity as a chance to prove to herself that she was capable of doing the job well. Her journal entries suggest low self-esteem as illustrated by the comment:

“Whenever you go and build something up, there's always someone to break it down....I feel like, if like the whole world failed me, because I'm always second or last although I'm doing my best.”

Jeanette described her thoughts about the project as such:

“This study was an eye opener and a feeding scheme to me. I could reflect to my own abilities and improve on the shortage in my life. Oh yes, of course, a feeding scheme not just because I received a package at the end of the month – no but a

feeding scheme that I can eat off and share the delicious food and puddings with my family, my household, and my neighbors, friends, and fellow residents.”

Mastering the research process

Part of the community researchers’ responsibility included contacting the mothers and daughters who expressed interest in participating in the study. Many homes do not have landline phones and many residents still do not have cell phones; thus, arranging an interview proved challenging as indicated by Valencia’s comment:

“...it’s very hard to get hold of the participants. They are either working or are out somewhere. I get relatives answering the phones, but who don’t give the messages. I called again. One woman didn’t come back from her outing this weekend. It seems like, the more we’re getting to the end of this year, the more they’re not available.”

Another entry from Valencia indicated further challenges involved when contacting mothers via telephone, “I’ve called one mother; her husband answered and went down my throat immediately. He wanted to know who I was, where I’m staying, and what I want.”

Most residents made use of public transportation, and their availability during the week was limited. Mostly, interviews had to be scheduled over weekends, which clashed with their personal calendars. Jeanette found working on weekends to be an imposition on the time she would normally devote to her family and said, “I don’t have the time to spend with my family anymore.” The actual work load and the administrative aspects of conducting research caused some of the researchers concern and stress. Marel wrote:

“I received two pairs of interviews that I had to do from Rachel (coordinator). I finished my first pair on the 22 November and the other pair on 23 November. It was so exciting for me finishing it in two days. I just hope my work is up to standard and that there won’t be any complaints”

The anxiety caused by having their work reviewed was mentioned by several of the community researchers. Jeanette wrote that although the initial critique from the coordinator had a negative effect on her, she later saw the critique as a valuable learning process. Later on in her journal, she wrote about the positive critiques from the investigators and how they inspired and motivated her to push herself to improve further:

“With the positive feedback from [PI] I am beginning to see qualities in me that I was not aware of before. I am beginning to have expectations of myself to reach the project goals. I must admit that I always had a low self-esteem and I always thought I could not please anyone. However, now the more I am aware of my good work, the more I have passion and not only for the money on the project”

Kaya wrote about the general stressors of conducting interviews in a community lacking so many resources. She wrote,

“Part of my experience while doing this project is that it can be stressful a lot and it’s not just about interviewing people, it’s [what] you hear and see from them. It does affect you because some of the things you hear and see, you may think it’s ok, but when you get home you think and it starts to haunt you.”

The community researcher as insider and outsider

The community researchers were directly confronted with the social and political context of their environment. For example, during the data collecting phase of the study there was a national taxi strike. During these strikes, the taxi drivers threatened commuters in order to deter them from using other modes of transport. The community researchers were dependent

on public transportation to get to interviewees' homes and, subsequently, were curtailed by the strike. Some of the frustration and fear from the taxi strike can be seen in Kaya's comment about the strike:

"...because of the strike I had to postpone [the interviews]. It was scary because they were beating everyone who was traveling and they burned buses and stoned train carriages. You know a lot of things happened this year. ...and they damaged a lot of things and killed a lot of people. In my street a lot of people who were security guards were beaten up and their lives were threatened."

Valencia also had four interviews scheduled during the taxi strike. She went on foot and said that she walked all day long, "...had no way out. My feet are very sore. I went to four houses today and they [were] very far apart from each other. [The] whole day gone."

Community researchers shared their thoughts on the research process itself. Kaya wrote about having difficulty with remaining objective and maintaining emotional distance between researchers and those they research:

"you know, research is something that community people believe and think is for educated people and rich people. You know when you visit these homes you definitely change and put yourself in their situations, they become a part of you. And whatever they tell you it affects you big time."

Despite the clear tension between science and social reality that the community researchers experienced, many felt that they learned valuable transferable skills. Jeanette wrote that she learned a tremendous amount about interviewing, thereby improving her confidence. She wrote about what she had learned about the nonverbal language of participants, and how to build rapport make her participants feel more comfortable and at ease. She discussed the importance of trying to relate to everyone she interviewed. She also wrote about the challenge of the language for her. Although she did her interviews in Afrikaans, her native tongue, the project used English as the language of training since this was the one common language amongst the community researchers.

Personalizing the research focus – the mother-daughter relationship

Interviewing mothers and daughters led the community researchers to reflect on their relationships with their own mothers and daughters, as well as relationships with other family members. For Valencia, learning about the lives of the mothers and daughters she encountered in the study made her grateful for her own close knit family. In her journal, she constantly mentioned her supportive family, as if to contrast it with some of the families that she interviewed. In contrast to Valencia's entries, Jeanette's interviews with mothers awakened her thoughts on the nonexistent relationship that she has with her mother.

Researching others.... finding myself

Closer to the end of the project, several of the entries suggested the community researchers started to develop a different, and perhaps more personal, relationship with their journal. This progression is especially evident in Marel's entries. Marel described a life fraught with financial and emotional problems. Her financial burden was further compounded by her son who has special needs. Perhaps as a way to relieve her own challenging situation, she dreams of meeting Zola, a television show presenter, and being on his show, *Zola Seven*. For Marel, her journal became a confidant; an anthropomorphic entity with which she shared her anxiety about her own well-being in the context of her family:

"We are a happy family, except for me. I still have to deal with issues that I only know of. I don't want to burden my family with what I'm dealing with inside. I

don't want to take that happy smile off their faces. Their smile gives me the strength to go on..."

Kaya's entries also show personalization of the journal, as demonstrated by her entry in which she calls her journal "bookie."

"Hey, bookie or should I call you friend? It's been a longtime since I have spoken to you. You know I've missed this. The sharing, I've thought about me sharing stuff with you. I haven't been honest with you about other stuff that's been happening to me, but I think I can trust you now."

Kaya also wrote about what she had learned from conducting interviews as shown in her statement, "the kids that I saw for my interviews were amazing. I've learned quite a lot from them." Myrtle shared very revealing and personal information in her journal, clearly using the journal to share some of her most intimate experiences. One such experience she shared reads as follows:

"When I came [to] Cape Town my life became more disadvantaged because I was raped for 5 years by the father of this house I was staying in. And I never told anyone because he used to tell me that if I ever tell someone he will kill and bury me [some] place where no one will see or find me."

She later wrote that she decided to tell someone but with no positive results: "I told this mother I was staying with and she thought that I was trying to embarrass her husband. So she chased me away."

Jeanette wrote in her journal how being part of this research project helped her focus more on her health. She wrote, "about my own health, I was never very particular about [my health] but now I believe that I will even become more health conscious and to put myself first and to think of myself as important."

Further discovering my community

In their role, the community researchers encountered many different social problems and they subsequently discussed a variety of individual and community challenges that they witnessed including gang affiliations, drug use and teen pregnancies.

"...when you open your eyes in the morning you hear about someone who has been murdered last night or a baby girl who was raped by a grown man. I think it's because of this place we're living in, that makes me so depressed. Maybe I'm too emotional but everything is getting too much to bear" [Marel].

Kaya wrote about being disturbed by the high rate of teenage pregnancy:

"There is also a high rate of teenagers' pregnancy especially from the two schools that we are interviewing. They are so young, cute, and brilliant. I don't know whether they are not scared of HIV/AIDS - because it really kills. They are in a free country where there are condoms and preventions but, still, they are getting pregnant."

Valencia also described how sad it made her to see "many (lots and lots) of young girls standing in line every month to get child support." As an ambulance driver she often transports young girls who, "are in labor and who are giving birth for the second or third time." She linked the issue of teenage pregnancy to sexual abuse and the high incidence of HIV AIDS in the community.

Substance abuse is also a common issue faced by the community. Kaya considered the spreading of HIV AIDS, teenage pregnancy, gangsterism and abuse of alcohol and drugs to

be the result of poverty. She lamented that Masidaal has only one day hospital and one clinic where on average 5000 people are treated per month. “You will find in one street there are about four shebeens (unlicensed drinking establishments) running and parents who are sending the 10 year old to go buy drugs for them.”

About crime, Lerato stated, “I don’t understand why/how can you kill each other as if you killing flies. I don’t know whether it is because of being unemployed or what, but the majority of the killers are teens.” In another journal entry, Lerato recalled how she went to visit her family in Cape Town to show them her computer certificate that she recently earned. However, upon arriving at the family home, the mood was extremely somber and she found her cousin crying on the sofa. She learned that her cousin had been diagnosed HIV positive. Lerato wrote,

“She is so young and she has got a two year old baby boy. I was so stressed, she was very straight, she didn’t cheat, and for the father of the child; she waited for him for the whole year just because she loved him and trusted him. The father of the child is staying in Joburg permanently; he only comes here maybe two or four times a year.... I was so furious for the whole day; I really don’t know what to do anymore.”

More than just a job – towards personal and community empowerment

Although for several of the community researchers, work on this project started out based on simple economic need, their tenure on this project, which lasted about 12 months, impacted them in a variety of ways. For several, it helped them gain tremendous self-confidence. According to Myrtle, her life had reached rock bottom when she joined the project. She described the process of gaining the research participant’s trust as therapeutic for her. Partly due to the financial gain as well, she started trusting her own abilities. For example, she stated, “As from my childhood everybody used to tell me that I’m stupid. I learned to be stupid and I end up being stupid. Now I can be on my own and do things on my own and do things on my own for me.”

Marel, Jeanette and Kaya felt that, they learned a lot and acquired basic communication skills that could benefit their personal and professional development. Jeanette summarized her growth as follows, “Through this project I could dip my own brush in my own soul and paint my own nature into the pictures that is mine. I learned that I can do anything if I have enthusiasm and this is the yeast that makes my hope rise”

Myrtle grew up being told that, she was not capable and would be unsuccessful. She felt that the project restored her confidence in her own capability. She wrote,

“[This project] made me a person that I never knew that I can be. [This project] showed me that there is something that I can do. And now I registered to do an office administration course. What I always dream about is to see myself being a web design specialist one day. The group I have or the colleagues I have [the team] are very special to me.”

Jeanette and Kaya found that, being confronted with the community’s problems was educational. It made them reevaluate their roles as community members, and challenged their level of community activism. In reference to the young girls that she interviewed, Kaya wrote:

“What is going to happen to them...? This project has brought issues to my attention that is really affecting our community. Late this year I joined a community health forum and I was nominated as secretary of the forum.”

Kaya appears to have gained strong insights about both her own role in the community, as well as the community itself. She indicated that, being involved in this project as a community researcher highlighted issues that affect her community, which she feels she must address. As she said, “It [is] sad to watch your community people not having the useful information they need when you know that they are in danger.” Jeanette summarized her growth from the project as follows:

“Skills that grow from depths to the deepest are just to mention a few – organization, listening, talking, writing and team work. Through this project a person could learn on every platform (e.g. the home visit – you as the interviewer were given the privilege to make people at ease in their own homes, [in their] environment and never mind your background, beliefs, cultural beliefs and values).”

Discussion

Community researchers do not enter the research endeavor as objective bystanders. In this project, we quickly learned how the difficulties of living in a poorly resourced neighborhood and having personal challenges can be exacerbated when stepping into the role of observer and researcher. Community researchers were asked to keep a journal and write down their experiences throughout the research process. More broadly, the journals illustrate how researcher and community member roles interweave and mutually affect one another, as well as how neither one of these roles can go unaffected by the hardships evident in a resource-poor, socially fragmented community such as Masidaal. In this section, we highlight some of the key issues that emerged during this study.

One of the major challenges for the community researchers was to master the roles and competencies required to conduct the research. Their initial anxiety and self-doubt required a lot of support but their journal narratives suggests a greater sense of mastery towards the latter stages of the research. A far bigger challenge was the tension raised by being both a researcher and a community member. The “insider” status of the community researchers informed various aspects of the research plan as well as provided valuable input especially with regard to the development of the interview schedule. The community researchers faced two struggles, their own personal struggles coupled with the emotional stressors induced by their increased exposure to the conditions in their community. A common response from the community researchers was to become enmeshed in the trials and tribulations of those they interviewed and their accompanying desire to facilitate tangible aid to the research community. The research team’s response to manage this strong identification was to focus on creating boundaries and some level of scientific distance while at the same time providing emotional support through journaling and the availability of the psychologist-led support group.

However, the focus on objectivity and boundaries, while well-meaning on the research team’s part created a dilemma for some of the participants. They felt restricted by the semi-structured interview format which required them to complete all the questions in a certain order. As a result, they felt as if they were not doing enough to address some of the issues they were witnessing during their engagement with the community. This dilemma on the part of the community researcher challenged the investigator’s own scientific framework about the boundaries for their own involvement with the researchers and community.

The journaling process emerged as a powerful vehicle for community researchers to have their voices heard. The journals facilitated a strong level of personal empowerment and the ability to identify the commonalities and differences between their personal lives and the research community. Certainly, the appeal to use their real names and the increasing

intensity of personal disclosures may suggest that the journals (and the research process more generally) provided an opportunity to break personal ‘silences’ and provided a chance to tell their story. These research journals emerged as having an important therapeutic function as indicated by the especially personal confidences that were shared. Journals can have multiple functions, with the three main forms identified as spiritual growth, therapeutic, and transformative (Epple, 2006). Journaling can also have application to multiple groups, including the disabled, youth, and immigrants. The use of these journals resonate with what Ira Progoff and others describe as having transformative and therapeutic value (Gestwicki, 2001). Drawing upon Michelle Fine’s work, one aspect of research engagement in participatory research is the necessary development of critical consciousness (Fine, 1992). Research journals with members of marginalized groups can provide an opportunity to critically explore the more difficult analysis of power relations within the team as well as the larger community. Consequently, not framing the use of these journals as a tool to facilitate critical thinking was perhaps an oversight by the research team.

It is vital to consider that apart from adopting the dual role of community member and researcher, the community researchers also adopted the role of research participants when they agreed to allow access to their journals. The timing of this added role is significant. Since we waited until the end of the study before asking the researchers to share their journal content with us, we minimized the potential for the employer/employee relationship to unduly affect the researchers’ capacity to freely deliberate whether or not to share their journal content with us. As Malacrida (2007) has pointed out, the employer/employee relationship places research staff into a subordinate position that can complicate the voluntary nature of research participation. Unlike in Malacrida’s (2007) study, the community researchers in our study were approached with the request to use their journal content only after their term of employment with the project had ended, thus avoiding any potential confusion that what was written in their journal would be read while being employed.

This study highlighted a number of challenges that can be encountered when conducting research in low-income communities. For example, the community researchers’ struggle to respond to the conditions in their communities resonated with the research teams own struggle with descriptive research and the notion of data collection first, intervention later. One of the dilemmas for the research team and other researchers to consider is how much emotional support is enough, the range of applicable support, and the duration of the support. Another question to consider is how does one respond, besides providing emotional and professional support, to personal disclosures such as rape or incest from the community researcher? There are no easy answers but there are likely many different answers. What is clear from this research is that a more fluid demarcation of researcher roles and responsibilities are required to effectively respond to these needs. Likewise, in reporting the narratives we also struggled with finding the balance between breaking the silence about community hardships and the research value of the disclosure.

While we believe we complied with research protocol on the one hand, and respectful and authentic communications on the other, the more profound issue is the extent to which power manifests in research settings between researcher and research participant. Despite obtaining their permission to use their journals and the timing of journal collection, it is undisputable that there was an element of cooption and differential power dynamic at work throughout this process.

First, in spite of stated intentions to empower the community researchers, how do the different positions, that of middle class researcher and marginalized community member influence the power dynamic, and, subsequently the permission to use the journals as well as

what was written in the journals? Secondly, in any research with marginalized communities, the question of data ownership and acknowledgement is critical. A limitation in this study was that there was no explicit discussion beforehand of joint ownership or authorship of the journal data. More importantly, in our compliance with human subjects' regulation and concern for protecting their identities, we missed the opportunity to engage in an in-depth discussion of the appropriate acknowledgment of their research involvement.

Conclusion

Global health research stands to benefit from the employment of local community participants in the conduct of research and the production of scientific knowledge. "Insider" perspectives and relationships can be maximized in the pursuit of timely and rich data collection. Yet, at the same time, community members enter into a unique and complex relationship with investigators, the research, and their own research community when adopting the role of community researcher. The journal entries from the community researchers in this study reflect this unique and complex relationship with their multi-layered stories of personal challenges, family lives, needs, wants, beliefs, and fears. Beyond their function as personal diaries, the journals tell a story of a suffering community and, in many cases how their authors felt powerless to make a difference in this community. The increased use of lay persons to conduct research within their own communities (geographic, disability, disease-specific, etc.) provides a critical impetus to further understand the potential impact of these conditions on lay persons and the research process. Training programs for community researchers should be enhanced to include consideration of the emotional impact of research and resulting feelings of helplessness. More broadly, investigators ought to consider the prospect of indirect benefits to communities, advocacy and social action as a means to allay some of the concerns of fieldworkers. Such steps can help reconcile the dual and somewhat oppositional roles that fieldworkers are expected to fulfill, namely of impartial scientist or researcher on the one hand, and invested community person and "insider expert," on the other.

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Research Highlights

- Explores the effect of conducting research on community or peer researchers in the context of an international health research study
- Critically examines the effects of research that emphasizes objectivity while exposing individuals to the subjective world of community life.
- Evaluates how journaling may help the community-based researcher grapple with the research process
- Critically reflects on the ethical issues related to the process of utilizing journals generated by community researchers or community-based research teams.

Table 1

Description of Community Researchers

Community researcher	Age	Work status	Family
Marel	40	Unemployed	Husband, Son, Daughter
Lerato	22	Worked as a waitress	Single. Living with her aunt for one year. Rest of her family not in Cape Town.
Valencia	29	Worked on the emergency services ambulance as a volunteer	Single, no children, Living with parents
Jeanette	35	Volunteered at library	Married, Children
Kaya	30	Worked part-time in a non-profit organization	Single, living in the backyard of her family's home. Has one child. Six nieces and nephews living in the home.
Myrtle	40	Housekeeping part-time	Boyfriend, baby son