

Community Engagement — A Complete Package: Needs Negotiation, Data Dissemination and Beyond

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Abstract

The success and effectiveness of community-based participatory research relies on a perpetual system of interaction between researchers and community members. Challenges that impact this cyclical process may arise: (1) in the initial needs assessment and when identifying a research agenda; (2) throughout the data collection and analysis of outputs; and (3) in the data dissemination phase. Equally important in community-based research is the integrated focus on capacity building and sustainability of the initiative. In this paper, our goal is to critically examine the challenges associated with effectively engaging low-income, research novice or skeptical communities in the research process. We explore our approach, experiences, and challenges in each of these critical phases and we discuss the implications of community engagement on the research agenda.

Academic-based researchers and community members bring different skill sets and resources to the interface. Effective community engagement is precipitated by the non-hierarchical appreciation of these varying skills. Honest communication of researcher and community needs and expectations can greatly facilitate the research, the outcomes and the potential for inclusive community engagement. The extent and nature of communication engagement is partly organic but at the same time requires organisation and judicious groundwork, especially when the research issue is not a primary perceived concern of the community. Capacity building, cultivating local human resources, in all facets of research is critical to create a sense of ownership about the research focus. Touting community engagement presupposes that the researcher is prepared to be flexible, a good and humble listener, and accountable. Researchers are in many cases 'outsiders' to the targeted community and must therefore be careful not to impose their expectation of the appropriate level of community engagement. Researchers and communities communicate from different vantage points; the key is respectful negotiation and creating an environment where mutual learning is encouraged.

Keywords

Community engagement, capacity building, needs assessment, data dissemination, accountability

Introduction

The success and effectiveness of community-based participatory research (CBPR) relies on a perpetual system of interaction between researchers and community members. Challenges that impact this cyclical process may arise: (1) in the initial needs assessment and when identifying a research agenda; (2) throughout the data collection and analysis of outputs; and (3) in the data dissemination phase. Equally important in community-based research is the integrated focus on capacity building and sustainability of the initiative. In this paper, our goal is to critically examine the challenges associated with effectively engaging low-income communities that have had little prior experience of research and that may be skeptical of the research process for a variety of reasons. We explore our approach, experiences, and challenges in each of these critical phases and we discuss the implications of community engagement on the research agenda.

Background

The need to build trust and rapport with the community may be time consuming, but is a necessary step in engaging disenfranchised community members (Israel et al. 1998; Minkler 2004). The research project is an inherently time-consuming task, which has a direct impact on the availability of community members. The philosophy and ideals of CBPR are applicable to many research agendas especially those that focus on low-income, disenfranchised communities. However, the challenges associated with this philosophy especially when conducting academic-based research are legitimate and often pose immense challenges for researchers who subscribe to the basic principles of the CBPR philosophy. Reaching a common, workable agenda, developing common goals and objectives, focussing on issues that are important to the community, while coping with funding and institutional requirements are some examples of these challenges. In poor communities, there are many pressing health issues, social stress, ubiquitous violence, as well as an immediate need for economic and political empowerment (Israel et al. 1998; Kawachi et al. 1997; Minkler 2004; Williams and Collins 1995).

Laying the foundation

Who initiates the research question? The development of the research question is perhaps the first step that highlights the differing resources of researchers when compared with the community. In most cases, it is the academic-based researchers who identify the research topic to be studied (Green 2004; Israel et al. 1998; Minkler 2004; Wallerstein 1999). This initiative is promoted by virtue of the fact that this is what academics do, and they often do it well. Secondly,

the researcher's interests, as well as available funding dictate the nature of the research question. In a few cases, there has been a synergistic effort where both the researcher and the community jointly decide on the research focus (Mullings et al. 2001).

However, this existing and most likely continuing discrepancy between researcher capital and community is an anticipated outcome of disparate resources and interests (Naylor et al. 2002). The more compelling concern is how the epidemiological data, research interests and different resources are effectively used to establish a discourse and collaboration with the targeted community. Often it may not be that the researcher and the community will agree on the importance of a research problem (Green 2004; Israel et al. 1998; Minkler 2004; Wallerstein 1999), which then begs the ethical question of whether this makes the research focus any less important. The research question is only an entry point for discussion with the community and this must be seen as an asset that researcher can bring to a community. From this point, it is critical that the research focus and direction of the research be equitably negotiated.

Community advisory boards

The difference in tangible resources and skills sets between researcher and community is an additional reality. Problems often occur when these skills sets are vied against each other and, more often than not, it is the community's skills that are underrated (Caldwell et al. 2001; El Ansari et al. 2002). This contention, often implicit and unrecognised due to its entrenched nature, by researchers is a recipe for disaster. Effective and well-functioning community advisory boards have the potential to equalise the context and can ensure that varying perspectives are considered. In particular, they are also an invaluable resource as 'cultural guides' of the target community (Minkler 2004). The tasks and purpose of the community advisory boards needs to be negotiated and understood. Unavoidably, some members of community advisory boards may have their own agendas, and similarly, some researchers may have their own agenda. It could also be that a researcher merely wants to use the legitimacy of a community advisory board to facilitate community support.

In community advisory boards where the researcher initiates the research, or assembles the advisory group, the tensions associated with insider and outsider might be present. Issues associated with race and class may be present and must be appropriately addressed. Power differences are present in all communities, but become particularly relevant in CBPR initiatives that bring 'outsiders' into negotiations with 'insiders'. Unspoken conflict and resistance to 'outsiders' can be manifestations of historical experiences or internalised oppression (Israel et al. 1998; Minkler 2004).

Community engagement through data collection, analysis and data dissemination

The goal in CBPR is to have high levels of community participation in all aspects of the research project (Holkup et al. 2004; Israel et al. 1998; Minkler 2004). Many community-based research projects are quite effective at gathering a group of community stakeholders in a community advisory board capacity. However, there is even less effort directed at including community members in the data collection or the data analysis process. There have been various attempts to involve the community in the data collection process (Naylor et al. 2002; Santos et al. 2001; Smith et al. 2002) but there has been a less concerted effort at engaging the community in the data analysis process. Academic-based research presents some obstacles that can unintentionally create tremendous difficulty for the CBPR researcher to easily utilise community members in the research process (Caldwell et al. 2001). For example, the checks and balances system utilised by the institutional review board of universities that effectively protect human subjects is absolutely necessary, however in communities where there are low levels of literacy, it would be challenging for community members who might be interested in participating in data collection to pass the human subjects test required of those who collect data from subjects.

Data analysis is another part of the research process that can reduce the barriers between research and community and additionally it has the ability to enhance ownership of the research project. Nevertheless, for many community participants the actual performance of data analysis is an undesirable responsibility (Green 2004) and for some the scientific aspect of it may appear too complex. Moreover, to many who are new to the aspects of research, the process may seem difficult, laborious and inconsequential. Though certain forms of data analysis may, by necessity, become the responsibility of outside researchers, no interpretation of the data should be done without involvement of the community members (Israel et al. 1998; Minkler 2004).

Dissemination of research outputs

The dissemination of research findings presents an interesting and as yet mostly unexplored conundrum for researcher and community members alike (Mullings et al. 2001; Severtson et al. 2002). When disseminating the outputs of the research initiative, potential ramifications (political, social, economic, ethical) within the community need to be thoughtfully considered. The use of a 'memorandum of understanding', which can be done either formally or informally, can be used to negotiate the best route for disseminating the research findings (Minkler 2004). The underlying goal of CBPR is to promote positive social change through sustainable community initiatives.

The CBPR cornerstones: capacity building and sustainability

Dialogue and discussion about capacity building and the sustainability of the potential outcomes of the research project must be a central concern from the very beginning of the project. These

key issues can potentially mediate the features of the intervention. At the same time, these critical considerations are often the most challenging aspects of the research. Capacity building in communities necessarily builds on community empowerment, which has the dual function of challenging the institutions and individuals who have power 'over them' and expanding the power of the community to act for social change (Wallerstein 1999).

Capacity-building can be considered a 'parallel track' in CBPR programs (Labonte and Laverack 2001). These researchers have found three essential conceptualising definitions of capacity building within the CBPR literature: (1) the development of health-related infrastructure and services; (2) the development of sustainable health programs; and (3) the enrichment of 'problem-solving' capabilities in the community and its representing organisations. The latter of these definitions is the broadest and most encompassing, allowing for inclusion of the former two concepts of capacity building as aspects of a generalised approach to building capacity in the community. For example, problem solving capabilities within the community would entail the range of activities from identification of the health concern, to the development of an action plan for dealing with the concern and the implementation of the planned action. Capacity building both subsumes and creates the concept of empowerment for communities, while encouraging sustainability of health promotion programs. In this view, the outside researcher or agency should be rightly viewed as 'enablers' who can provide material, financial and human resources and access to more powerful networks (Labonte 1997).

The question of creating sustainable change or impact long after the initial research has been completed, the original funding has ended, and the academic papers have been published remains one of the more critical concerns to researchers committed to a CBPR philosophy. Policy changes is one form of creating a lasting and positive impact as it was in the Seattle intervention for improving childhood development, which had positive policy results (Horsley and Ciske 2005). Furthermore, academic–community partnerships have several benefits in that they can facilitate sustainable improvements in health, such as providing improved child care through the training and employment of public health nurses as consultants and establishing reasonable funding mechanisms to sustain the program within the community (Gaines et al. 2004).

This paper draws upon our formative research in an urban area of the Western Cape in South Africa comprised of Blacks and Coloreds. Although the *Population Registration Act* of 1950, which authorised registration by race, was repealed in 1991, the majority of South Africans continue to self-identify by race. Our use of these racial categories reflects the historical background of participants, their continued attempts at self-identification, and the remaining legacy of apartheid. The framework that guides this discussion includes the 27 focus groups that

we conducted with 181 girls and boys in Years 8 to 10, teachers, mothers, support staff and educators. We recruited participants from the four senior secondary schools in the targeted community. In addition, this paper also draws upon our experiences gained from our informal interviews with stakeholders, numerous field visits, and surveys with mothers and daughters targeted at the overall goal of developing a community-based cervical cancer intervention. The goal of this research was to explore the pertinent health concerns of young girls in this community in order to develop a targeted community-based intervention that would educate them about the risks for cervical cancer. In this paper, instead of discussing the results of the focus group data, (these details are described elsewhere (Mosavel et al. in press)), we specifically focus on the *process* we engaged in to conduct this research and its implications for community engagement. We started our work in this community in March 2003. The process described below includes what has happened since then.

Process

This research utilised a mixed-methods approach, including field visits, informal interviews, and focus groups to explore the socio-cultural, political, and economic factors relating to the implementation of a cervical health promotion program. The targeted community was chosen based on various inputs from community stakeholders and cancer prevention specialists who work in the Western Cape region.

Utilising a community-based approach

The decision to utilise a CBPR approach was synergistic and (initially) intuitively and wholly based on our experiential knowledge of the target community. Our knowledge was in particular informed by having lived most of our adult life in South Africa and thus we brought our personal understanding not only of the South African political, racist, history but also the critical consciousness culture of many local disenfranchised communities to our conceptualisation of the research approach. We recognised that the targeted community did not have a vast experience with scientific and behavioral researchers, and that if they did have any experience with researchers from abroad, it was more than likely to be an 'in and out' or 'fast food' experience. That is, where the researchers enter the community with the sole purpose of collecting data, collects the data, and then is never heard from again. Our guiding objective was not to leave the same legacy.

Decided on the research question

The research focus was dictated by the co-investigators' interest and research experience in cancer prevention and control. Among other factors, this particular interest, combined with the epidemiological data that underscored the disparate cervical cancer incidence and mortality

among South African Black women, guided us to do our work in South Africa. As we were doing initial investigation into this area, we realised that cervical cancer education was lacking among adult women of colour, and that there was limited, if any, focus on educating young girls about risk behaviors for cervical cancer. Notably, prior to our official decision to use our existing research funds to focus on cervical cancer prevention in South Africa, we started collaborating and discussing research options with a community activist in South Africa who would later become our project coordinator.

Negotiated the research question

On our first site visit to South Africa we met with various stakeholders, primarily to introduce ourselves and to discuss the epidemiological data and our research ideas. Consistently we received feedback that an intervention that focuses only on cervical cancer in communities with multiple health problems would be largely ineffective. We were unprepared for the strong emotional reaction that talking about cancer prevention would engender within communities with other, more serious health issues. Our surprise was not as much driven by the emotional reaction to the term 'cancer', for the literature is rich with instances where communities react very emotionally to this subject (Bingham et al. 2003; Brunton et al. 2005; Jennings 1997; Noor-Mahomed et al. 2003), rather our surprised and learning stemmed from the recognition that the wording of our proposed research initiative 'cervical cancer education/intervention' suggested the absence of a broader understanding of the community's health needs and concerns. In this targeted community, violence, HIV AIDS, asthma and tuberculosis were among the more serious health concerns.

Like many researchers, our research agenda is driven largely by our funding source, and knew that we were only allowed to focus on cancer and not for example tuberculosis (Classen et al. 1999; Ellis et al. 1997) or diabetes (Chopra et al., 2002), which are significant health issues amongst blacks in urban areas in South Africa. However, after meeting with university researchers, health providers, community members, parents, youth we fully recognised and accepted that the community was telling us that the terms or framework we use within which to examine our research interests is critical and need to include the realities and concerns of the communities. Thus, we coined the term 'cervical health' to imply a broader recognition of these other health issues. The community had spoken and they told us that cervical cancer in isolation of their other health issues was inappropriate. Instead, they recognised that a cervical cancer intervention has to be relevant to their lives — lives that are punctuated by poverty and hardship. In this initial and critical phase, we learnt the importance of labeling, framing and how the language used to convey the research question speaks to the orientation. On the other hand, the concept of 'cervical health' puzzles our US-based university officials, funders and other

academics. Encouragingly, other academics in the United States working with disenfranchised communities have used the concept of cervical health for similar reasons (Smith et al. 2004).

Conducted numerous and varied informal stakeholder meetings

Our CBPR approach led us to meet with a wide range of local stakeholders in the initial stages of our investigation, in order to establish rapport with the local community and to invite feedback on our research objectives and research plan. We also conducted ethnographic observation at community schools, the local clinic, the library, informal social halls, local businesses, and other venues. The goal was to introduce ourselves to a diverse range of community stakeholders, share our research interest, and provide stakeholders with an opportunity to question our intentions and goals. This deliberate effort to open ourselves to scrutiny allowed us to learn about and address the possible fears, misperceptions, and expectations of the community. For example, often educators expressed that they felt overwhelmed and their response in essence was “yes, yes, do whatever you can with these kids, they need help.” This expectation could have been driven by the desperate need for any type of intervention or it could partly have been driven by the perception of us as researchers from the United States.

During our initial meetings when our goal, naïvely, was to merely share our research agenda, most of the community members, youth, educators, and parents wanted to know more about the clinical aspects of cervical cancer, they wanted to know what they needed to do to prevent cancer, they would talk about incidences in the community where individuals had various kinds of cancers. This was another important lesson in that if we come into a community focussing on an anxiety provoking disease (Kim et al. 2004; Ogedegbe et al. 2005) we needed to be willing to allay people’s fears and to provide them with education such as pamphlets or contact information of health providers. Additionally, we were also time and time again had to deal with grandiose perceptions of us, being from the United States, as having unlimited funding opportunities. This provided us an important opportunity to explain the competitive funding environment in the United States and that our work in the community was largely dictated by our ability to secure funding. During our initial entry into the community, we realised that this stage of ‘getting our feet wet’ was as important as anything we planned to do in the implementation of our ‘actual’ research.

Nonetheless, we left from our first site visit with the overwhelming sense that we needed to start slowly and that even with our supposedly enlightened attitude and experience, we still made too many assumptions. Our first goal then was to conduct the focus groups to understand the overwhelming issues of the community. We purposely had a broad research question because we wanted to understand the community’s perception of the factors that influence healthy living.

Education, responsibility, and accountability started the minute we made a decision and were allowed access to the community. In fact, on subsequent visits, we heard talk of women whom we had spoken to before and who had since been diagnosed with cervical cancer. We heard about women who had gone for a pap smear because we said the words “cervical cancer and pap smears.” Moreover, we had different women approach us with more direct questions about cervical cancer and some women whom we spoke with before had additional questions about cervical cancer. The latter group had not been to the doctor because of various fears and neither were they planning to; they just wanted to know more information from us. All this before any intervention has even been planned much less implemented.

The question of sustainability was foremost in our minds especially when we met with officials from the Department of Education, the Department of Health, as well as officials of the local health clinic. We talked about the possibility of incorporating information about cervical cancer in the Life Skills program of the high school students. We were constantly asking others and ourselves “how can any program we develop be sustained after the funding and the research has ended?” School officials have expressed an interest in incorporating cervical cancer education into the curriculum although no guarantee has been asked or given.

Established a reference team

In keeping with our CBPR approach, we established a community-based ‘reference team’ consisting of youth, parents, local health workers, university researchers, and government officials, to provide the community with a forum for contributing to our research process. The reference team was critical for various reasons. It allowed us to introduce ourselves to a large number of stakeholders who had a very important stake or were doing notable work in the community. At the first reference team meeting, several of the attendees mentioned that this was the first time that they had met many of the people in the room and that it was an ideal opportunity for them to network with each other. At this meeting, we informed the team about our meetings with other stakeholders and the information that we have gathered. We stated the purpose of the team was to advise, guide, and potentially shape the research. Furthermore, it was also an opportunity for us to work collaboratively and we indicated our willingness to share any relevant data collected. Since many members of the reference team were understandably busy, we decided to meet at least twice a year but that the coordinator would maintain regular contact with members of the group to give them regular updates.

Many individual members of this group provided direct assistance with the data collection and data analysis aspects of the research. Nonetheless, on the second occasion of assembling the group, we discovered that either several members of the group had accepted new job

opportunities, were no longer working in the community or that representatives of the organisations were no longer in that particular position. This, combined with the schedule of the investigator who was present during a particular time in South Africa, meant our second meeting was much smaller and in fact, because there were several new faces, it was as if we were starting from the beginning. In reality, the reference team did not function as we had hoped. The reasons are varied but primarily it was less than successful because of the lag time between meetings, not communicating a clearer connection between our research and their work, and especially the high turnover of staff. Although the group did not meet again in its (original) entirety, many members continue to remain involved and committed to the cervical cancer prevention project.

Data collection

In our research, capacity building primarily occurred during the data collection and data analysis process. Based on our community-based research approach, it was important to have members of the targeted community involved in the data collection process. We hired and extensively trained community members who were unemployed to become focus group facilitators and to conduct home visits to parents to discuss the study and to answer questions about the informed consent process. In our focus groups, we paired a community person with an experienced focus group facilitator. The ownership that the facilitators cultivated towards this research was unparalleled, and, in effect, these community members became involuntary informal educators about cervical cancer — for example, members of the community would ask them about their work with us or they would share of their own volition information about the project. Furthermore, these community members became familiar with the aspects of research and were able to successfully integrate their instinctive service delivery proclivity with the technicalities of research. Interestingly, many of the facilitators repeatedly expressed how astonished they were about the issues and the perspectives that many of the focus group participants shared. Several facilitators expressed that this data collection experience taught them that not only were they making many erroneous assumptions about their community but that they shared many common views with others (mothers, teachers, youth) than they had realised. This identical sentiment was expressed during our data dissemination phase as well.

Data analysis and using the community perspective

Data analysis was conducted using a workshop format in which members of the research team collectively discussed the focus group data with the aim of identifying and summarising the predominant themes and issues that were of concern to participants. Our analysis was guided by the study goal of assessing the overall health, and the factors affecting health, of young girls in the community for purposes of developing a cervical cancer intervention. The focus groups were

conducted in Xhosa and Afrikaans, but only the Xhosa focus groups were translated into English. The investigators were fluent in Afrikaans and wanted to maintain the natural rhythm of Afrikaans communication. This decision provided yet another opportunity to build community capacity by keeping some of the members involved in the project beyond the data collection phase. We provided additional extensive training to these members in the mechanics of qualitative data analysis. A South African-based researcher who communicated regularly via email with the researchers in the United States supervised the local analysis.

Research assistants in South Africa and the United States created comprehensive, substantive summaries of responses to each of the seven focus group questions. Each summary consisted of a quantitative list of response categories for each of the interview questions, and a qualitative synopsis of the participants' responses. Finally, each summary included the research assistants' personal interpretations of the responses to the question. Content analysis was then performed to identify the common themes across all groups. There was an initial learning curve for the South African data analysis team in that they had never done a systematic data analysis that required objectivity and abstract thinking about their own community. They were provided support and guidance and delivered high quality work. Likewise, the United States researchers also had an additional learning curve in that they had to learn about the South African context and in particular the framework within which to interpret the focus group responses. The opportunity to participate and review the analysis from such different perspectives further highlights the importance of community engagement in keeping the data interpretation accountable to the context or culture. Ultimately, we still interpret events, albeit objectively, based on our particular worldview.

Attempts at data dissemination

After collecting and analysing the data, we decided to conduct data dissemination workshops in the community. We returned to the community and met with as many of the stakeholders to communicate our focus group findings. Our goal was to demonstrate accountability and report back to those we spoke with in the initial phase of the research. We also hoped that the community would be interested in the data and to use it to lobby on their own behalf, including areas unrelated to cancer. The data dissemination phase had two main formats. One was a written summary report provided and the other was a verbal report that underscored the main findings of the focus groups.

We met with representatives of the Department of Education, Department of Health, school principals and educators. We also had data dissemination sessions with mothers, youth, reference team, and other community stakeholders. Again, we included community members in this phase to communicate the findings to some of the stakeholders. In the session with the

educators, mothers, the reference team and other community stakeholders we provided a verbal report, which underscored the main points that emerged from the focus groups. The goal was to make these sessions interactive and participatory. Seven members of the reference team attended the meeting and most were new to the research project after having taken over this role in their organisation from previous members of the reference team.

The responses to the focus group findings were in general positive. Most of the bureaucrats were pleased that we had provided them with a written report. The response in the separate sessions with youth, educators, mothers and other community stakeholders ranged from passive (not a lot of verbal feedback) to spirited. The passive response was primarily from youth who had a 'so what' expression. In retrospect, the researchers did not provide the youth adequate guidance as to what to do with this information. The intended goal was that the student representatives would share this information with the rest of their class. We neglected to facilitate this process adequately and could have provided posters or handouts. Youth are not often presented with feedback from adults on projects and therefore did not exactly know what to do with this information. Also, we found that in most of the groups, the response to the focus group data (that essentially dealt with the 'state of the community') was already well known in the community by virtue of the daily experiences.

Indeed the data feedback discussions were spirited but while we naïvely expected the discussion to be about the results, instead it was about cervical cancer — who gets it, why do they get it, what can be done about it and so on. The data dissemination meetings with the community (not with the officials) especially caused us to critically examine our research agenda in that it felt as if we have been spending considerable time doing formative research, primarily for the researchers' and funders' benefit. While our goal with the focus group study was to better understand the issues in the community prior to developing a cervical cancer intervention, it seemed that from the community's perspective this step was almost unnecessary as evidence by their unsaid attitudes of 'we could have told us so' a fait accompli, or 'we knew that'. There was nothing unanticipated to them about the high levels of crime, violence, risk behaviors and poverty in the community.

Nonetheless, what was informative across all groups we talked with about the data was their realisation of how similar the different cohorts felt and how disconnected they appear to be from each other. Mothers, teachers, and youth thought that they shared a distinctive view, which they did, but what they did not realise was how widely it overlapped with each other's perspectives. Another surprising lesson from the data dissemination sessions was the extent to which participants wanted to know more about cancer. Again, similar to the needs assessment phase, participants wanted to know more about the clinical aspects of cervical cancer or were eager to

share stories about people who have been diagnosed with cancer or are suspected of having cancer.

In future data dissemination sessions, we will have to plan more extensively and deliberately. A more structured approach aimed at gaining feedback from communities as to the meaning and value of the disseminated data would also be insightful. As researchers, we need to have a clearer vision about the outcomes of a data dissemination session. In this case, the data dissemination session effectively communicated the findings of our study. Furthermore, it was useful in demonstrating our willingness to be accountable even though in some cases we were greeted with puzzlement perhaps an indication of the community's inexperience with researchers returning to discuss their data. Or, it could have been related to the 'so what' question as in what are they supposed to do about information that they are already well aware of. In summary, data dissemination is an important part of the community engagement and CBPR process. However, this is an aspect of CBPR that needs more exploration especially the question of how the community can use the researcher's data to lobby on their own behalf. As more communities become used to researchers returning and sharing the findings, the less this practice will be looked upon as peculiar. As researchers, our role has mostly been to ask something of the community (i.e. participation, input) but the data dissemination phase is a component of research where we can provide the community with valuable data that can support their own community-based endeavors. Finally, although the community was understandably knowledgeable about the realities of daily life, it is essential that researchers/outsideers still acquaint themselves with the community's understanding and interpretation of daily life. The results of the formative research revealed not only the nature of daily lives but also highlighted the importance of the mother-daughter relationship, an area that we are currently exploring further (Mosavel et al. submitted). The context and understanding of a community's realities have significant implications for the type of intervention that is developed.

The Beyond

Low-income, marginalised or research skeptical communities are often concerned about the intentions of researchers and the commitment of researchers beyond the completion of the research project (Lichtenberg et al. 2004). Developing research agendas that have a lasting impact or have at least one aspect that is sustainable is ideal. In this community-based research project, we have often felt concerned given the considerable amount of time we have spent conducting scientifically sound formative research, while the pressing need to do something constructive about cervical cancer remains. If community members have similar concerns, they have yet to tell us. Academic-based researchers are driven by scientific and funding agendas and their continued research is dependent on the integrity of their science and future funding.

Although thus far we have only conducted formative research (we have returned to the community to explore the relationship between mothers and daughters and its feasibility for cervical cancer health promotion (Mosavel et al. submitted), we know from anecdotes that we have already influenced the health behavior and knowledge of some regarding cervical cancer. It can further be argued that we helped the community to place this issue on the agenda and that we created some momentum among other organisations about the need for education about risk behaviors for cervical cancer among youth. More recently, the Department of Health and the Cancer Association of South Africa used our report on our work and launched a day of cancer prevention activities in this community. An important aspect of creating the 'beyond' in community engagement and CBPR is to work within the context of the community and in effect to create the buzz about a particular research or health related issue. This 'beyond' includes the conduct of the researchers, the communication with community partners, and the investment in human capital. Researchers must realise that with each project, particularly in low-income communities, they create a layer of research memory, which will influence the way future research is seen in the community and influences future community participation.

Conclusions

The importance of listening to as many community voices as possible cannot be over-emphasised. The community engagement process presents difficult questions accompanied by a host of ambiguities. For example, what level of community involvement is acceptable, appropriate, and even feasible from marginalised communities? Should we interpret a lack of community engagement as a lack of interest? Many community participants live in stressful environments, which confound their ability to remain highly engaged in all stages of the research. Often those individuals who do become involved in community-based activities are the spirited community activists who are always available to attend a meeting or to do the necessary work. Providing a small number of residents extensive training on research projects and passing along their resumés could help to foster a sense of achievement and ownership not only towards the project but to the research issue in general. Capacity building and sustainability concerns ought to be part of the initial conceptualisation of any new community-based research project. If these two concerns are an integral part of the project, it can facilitate the wide range of stakeholders that are consulted and included in the process. Community engagement at all levels is critical for sustainability and capacity building. There are numerous challenges in community-based research especially if community engagement is regarded as an essential component. In our experience, the biggest challenge to our own identity and self-worth has been about the long time (two years) that we have conducted formative research in the community. Although the initial research was driven by a necessary and humble desire to understand the community better in order to develop a tailored intervention, our subsequent research efforts in the community have

largely been driven by funders (e.g. what will be fundable in the present day economic climate, what kind of international research is fundable, and what kind of intervention will be transferable to the United States). Another challenge to the research itself is driven by the international nature of our research. Undoubtedly, we have managed to secure an invested, community-oriented, and connected local project coordinator. We try to maintain regular telephone and email contact with the key stakeholders in the community and we have visited the site at least twice each year and in some cases more. However, it is a drawback when we cannot just drive several miles to visit the community. International research, especially community-based research, is extremely necessary, but the researcher has to make the additional effort to maintain a presence in the community. Most of the time we feel that we have done this successfully and, in fact, because we cannot physically be present, we have also given other project staff more opportunities to communicate on behalf of the project. Nonetheless, the truth is that most researchers are essentially outsiders, whether they can drive to the community or have to fly to visit the community. Accepting this reality may assist in making the researcher more reflective about their own privilege and assumptions about the community.

In summary, researchers need constantly to situate themselves in the research process and in relation to the community they are working in and with. The notion of openness to scrutiny, questioning one's own naivety and assumptions, and being prepared to admit shortcomings (e.g., in the data dissemination process and the creation of the community advisory committee), suggest that a truly complete package is one in which the researchers are cycling back information from the community and their interactions with community members to better understand how they, the researchers, ought to be interacting, making adjustments, improving on the research, and being accountable. This process requires a type of 'critical awareness' in which the researchers strive to reveal aspects of their identity, relationships to their subjects, motives, and limitations, that they may not previously have been aware of. Developing, maintaining, and nurturing this awareness throughout the research process — from the outset through to data dissemination and beyond — is a core aspect of community engagement as a 'complete package'.

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