Deconstructing participatory research in an HIV/AIDS context

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Abstract

Participatory research is frequently fore-grounded as an innovative approach to knowledge production, which, in contrast to the more traditional controlled research methods, engages participants in meaningful exchanges with researchers. In this article, we argue that participatory research has its own complexities and contradictions. We draw on data emanating from a research project aimed at mapping barriers to basic education in an HIV and AIDS context in the Richmond area, South Africa. Using post-structuralist notions of power, we explore constructs of voice, situated ethics, knowledge, emancipation and researcher reflexivity in order to determine to what extent and in what ways the use of participatory research methods is truly participatory.

Introduction

Our article is structured in four parts. Part one is concerned with a theoretical framing and a review of the literature on participatory research. In part two, we provide an overview of the Richmond research context. The research strategy we used to gather data from the cohort of researchers using participatory research methods is outlined, and constitutes part three. Our discussion of the emergent themes follows in part four.

Theoretical framing

Politics is at the top of the post-structuralist agenda (Cuff, Sharrock and Francis, 1998). Politics puts into question or play the methods of rational thought traditionally used to describe the world. It sees orders of rational thought as strategies of power and social control, as ways of ignoring reality, of stifling it rather than understanding it. The most radical claim of post-structuralism is to reject the possibility of arriving at a ‘truth’ about the essence of a phenomenon.
The rethinking of power by Foucault and others, as having multiple forms and micro levels, is important in rethinking the lives of children and of marginalised groups. Foucault asserted that power produced and controlled the epistemology, theoretical structure and taxonomy of formal knowledge, the cultural codes by which groups acted out their roles, and the valuable social discourses between diverse ethnic groups and classes of modern society. In *Power and Knowledge* (1980) Foucault provides an analysis of power:

> The idea that there is either located at – or emanating from – a given point something which is a ‘power’ seems to me to be based on a misguided analysis, one which at all events fails to account for a considerable number of phenomena. In reality, power means relation, a more-or-less organized, hierarchical, co-ordinated cluster of relations (p.198).

Foucault’s definition of power does not refer to the pressure based on police power with which the ruling class suppresses the other classes (sovereign power).

> What characterizes the power we are analyzing is that it brings into play relations between individuals or between groups [. . .] The exercise of power consists in guiding the possibility of conduct and putting in order the possible outcome [. . .] (Foucault cited in Dreyfus and Rabinow, 1982, pp.217–221).

Foucault reverses the traditional belief that knowledge is power and looks for power as the disciplining of individuals as they approach the everyday practices of their lives. It is viewed as inscribed in the rule through which people ‘reason’ *(and tell the truth about themselves)* about the world and self as they act and participate. In this sense, Foucault’s concept of power gives attention to the power as productive rather than as repressive and negative (Popkewitz, 1999). Power has to be positive (it transverses and produces things, it induces pleasures, forms knowledge, produces discourses) as well as negative. Power has to create new forms of behaviour, new modes of self-understanding, and new codes of meaning, as well as restrain behaviours opposed to a ruling class.

The exercising of power produces what is held to be knowledge; what is the right interpretation; the valid act or utterance within that practice. When power circulates it determines to some extent possible ways of acting and limits of what can be done; but it is also a mechanism that enables one to act (Cotton and Hardy, 2004). Power is something that can be used and brought together by particular people in specific situations through discourses. In this sense, power will not depend on specific groups or identities. Discourses embody the
meaning and use of propositions and words. Thus certain possibilities for thought are constructed. “Words are ordered and combined in particular ways and other combinations are displaced or excluded. Discourses get things done, accomplish real tasks, gather authority” (Said, 1986, p.152). Foucault believed that paying close attention to the details of practice, the sources of power and the discourses through which they are expressed, could tell us about the way power could be exercised. The productive elements of power move attention from identifying the controlling actors to identifying the system of ideas that normalise and construct the rules through which intent and purpose are constructed in action (Popkewitz, 1999).

One type of discourse, research, is acknowledged as one means of regulating society and is therefore political in the exercising of power. We were keen to explore how the researchers engaged with the views expressed by the participants, especially by children and marginalised groups, and specifically the ways in which power was exercised in the research process. We questioned the contextual power conflicts at work and how the researcher’s social positionality (intersection of race, class, gender, sexual orientation etc.) impacted on the research situation.

Given the asymmetries of power around the research process, theoretical movements around post-structuralism has also highlighted the development of the concept of ‘Other’. Deetz (1998), in discussing voice in relation to Foucault’s work claims:

Voice can be considered as an attempt to open discussion about issues that apparently need no discussion and to act on rather than simply in present institutional arrangements. Voice, thus is the presence of active resistance to consent processes. ‘Voicing’ opens both the corporation and individual to learning through reclaiming differences and conflicts overlooked or suppressed by dominant conceptions and arrangements. All discursive formations centralize particular concerns and interests and marginalize others. Dominant arrangements normalize people and events along the lines of certain interests. Voices reclaim that which was marginalized, putting it back into competitive relation with the dominant interests (p.159).

Previously silent voices are now being heard resulting in the emergence of new social discourses. Silences can be a potentially disempowering act. Silences can be manipulated and contrived in social contexts by other players and stakeholders. Such voices may be those who are in the lower socio-economic strata of society, those whose language and literacy skills are not recognised by elite society, those whose sense of self is low or under
developed (Ling, 2003), and those who live in poverty, far from newspapers, e-mail and consultative meetings. Human voices that exercise choices to act or not to act make a difference to the systems within which they exist (Ling, 2003). We were interested in exploring whether participation alone gives adequate voice to the participants. Whose voices are heard and whose voices are silenced by the social arrangements? What do the silences in the participants’ accounts reveal? To what extent has mastery in the participatory technique comprised the participatory process?

Another challenge for researchers working with children is the disparity in power and status between adults and children (Morrow and Richards, 1996). Working within a historical and cultural context in which children’s voices have been marginalised, researchers face great challenges in finding ways to break down the power imbalance between adults and children, and in creating spaces that enable children to speak up and be heard. The same could be said of rural communities deepened by extreme poverty in a context where HIV/AIDS prevalence is high. Participatory techniques are particularly advantageous in communities where there are low levels of literacy, as the methods of information collection do not rely heavily on reading or writing skills, but place greater emphasis on the power of visual impressions and the active representation of ideas (O’Kane, 2000).

Regarding specific participatory research techniques, Seidel and Coleman (1999) have made effective use of narratives and story lines in ‘envoicing’ HIV positive men and women in rural KwaZulu-Natal. Huber and Gould (2003) have used children’s drawings, including maps and time lines, to investigate school non-attendance of orphans in Tanzania. Other research involving participatory techniques illustrates different ways in which to establish effective communication by allowing children and young people to shape the agenda; by focusing upon real life concrete events; and by involving children in ‘handling things’ rather than ‘just talking’ (O’Kane, 2000). Methods that have worked well have included: drawings, mapping, flow diagrams, play, matrices, transect, drama, stories and songs (James, 1995; Nieuwenhuys, 1996; Chalwa and Kjorholt, 1996; Alderson, 1995; Sapkota and Sharma, 1996).

A participatory research approach to data production is an essential component of in-depth emancipatory research (cf. School of Education and Development, 2005). Such an approach enables the production of knowledge in an active partnership with the participants who are affected by that knowledge (Babbie,
Participatory approaches, according to Babbie, produce grounded knowledge through collaborative relationships between participants and researchers and by locating the research in a community. In seeking to involve participants in the research project, “participation does not simply imply the mechanical application of a ‘technique’ or method, but instead a part of a process of dialogue, action, analysis and change” (Pretty, Guijt, Thompson and Scoones, 1995, p.54). The successful use of participatory techniques lies in the process, rather than simply the techniques used. Thus, the genuine use of participatory techniques requires a commitment to ongoing processes of information sharing, dialogue, reflection and action (see Theis, 1996). As Chawla and Kjorholt (1996, p.45) observe, “participation may indeed be an empowering process, but the limits of the power need to be acknowledged to make the potential for real achievements clear”.

Consideration of ethical issues becomes paramount particularly when working with children and marginalised communities around sensitive issues. As such, situated ethics are a set of practices well suited to working with marginalised researched participants. In this view, ethical principles are mediated within different research practices, questioning the notions of scientific objectivity and value neutrality by recognising the socio-political context of all research (Simons and Usher, 2000). Gray, Lyons and Melton (1995) identify respect for persons and their privacy as key ethical issues in HIV/AIDS research. This is the case not only because of the stigmatisation and discrimination associated with the disease. Psycho-social research into HIV/AIDS involves highly personal and sensitive topic areas, and researchers need to exercise respect and circumspection in engaging with participants. This is accentuated because those affected and infected by HIV/AIDS are often the most vulnerable and marginalised social groups (Gray, Lyons and Melton 1995).

This calls for researcher reflexivity through every stage of the research process. Ethical issues allow us to question underlying assumptions, for example: What are the hidden values and interest? Who benefits from the research process? How is power used, abused and shared? Does the sample chosen enable participation by marginalised groups? Writing particularly in the area of participatory action research (PAR), Yeo (1993 cited in Hagey, 1997) states that social justice principles of equity, restitution and procedural justice are important concepts in PAR. Restitution acknowledges institutional responsibility in creating conditions that must now be rectified. The concept of procedural justice values how relationships are lived, how interactions exclude or refrain from including, how particular elite individuals holding office
practise dominance and perpetuate systemic disadvantage, how racism hurts and humiliates and is denied, how its perpetrators are unwilling to examine their own practices and how resistance to change is manifested, for example, when institutions have righteous sounding policies that they do not put into daily practice. PAR relies on honesty and veracity both in declaring agendas (reflexivity) and in carrying out the research and implementing its goals. On this foundation both validity and legitimacy are grounded (for a detailed discussion of PAR and participatory research as well as a review of participatory methods used in researching HIV/AIDS see School of Education and Development, 2005).

The Richmond research context

Richmond municipality is located in the uMgungundlovu District in the Midlands area of KwaZulu-Natal, about 38 km south-west of Pietermaritzburg. It serves the farming and forestry communities, and is surrounded by semi-formal and informal settlements and outlying farms and rural settlements. Census statistics place the population figures for Richmond Municipality at 62 108 people, of whom 53 per cent are female. Richmond’s population is relatively young with 47 per cent of the inhabitants between the ages of 0–19, and a further 20 per cent between 20–29. A concern is that 20 per cent fall into the high sexual activity age group. The Province of KwaZulu-Natal has the highest prevalence of HIV infection at 14.1 per cent. The rate of unemployment in Richmond is 38 per cent, which means that for those employed, the ratio of dependency is eight people dependent on every earner. Seventy-seven per cent of households subsist on less than R1 500 a month. Richmond came to prominence during the 1980s and 1990s as a flashpoint of political violence, first between the United Democratic Front and Inkatha, and later between the African National Congress and the United Democratic Movement. Political conflict has cost an estimated 20 000 lives in the province of KwaZulu-Natal since 1984. Richmond is, however, currently experiencing a period of relative peace and stability (KwaZulu-Natal Municipal Portfolio, 2005).

The research project involved three high schools, five primary schools, two adult basic education centres, a school for the deaf, and two early childhood (ECD) centres. The geographical location of the schools includes rural, urban, deep rural, and peri-urban areas. The participants in the study included learners, parents, and caregivers, school governing bodies, NGOs working in
the district, officials from the Departments of Health, Education, and Social Welfare, HIV support groups and volunteers, and out of school youth.

The larger research project is in the form of an in-depth qualitative case study located within a participatory research framework. The roots of this framework lie in the view that research and participation can be closely linked to collective investigation, learning and action. Verbal methods of inquiry are replaced by more visual methods of inquiry and dialogue. From this perspective, researchers have an interest in developing a greater understanding of the local knowledge and the local people can engage in a process of reflection about their own lives. As local knowledge consists of concepts and frameworks for understanding embedded in the local context, there is an assumption that local knowledge is closer to the ‘truth’ about the reality of a particular context (cf. School of Education and Development, 2005).

Prior to the project, a review revealed that much of the literature on HIV/AIDS in education has focused at the macro-level of national education systems within a quantitative research approach. In particular, this body of literature has drawn attention to the destructive impact of the pandemic on teacher numbers, learner attendance, and systemic management. Little attention has been given to the micro-level of analysis of the effects of HIV/AIDS on particular schools and communities, and of the concrete experiences and responses of educators, learners and parents regarding HIV/AIDS. A study by Huber and Gould (2003) suggested that micro-level research, using more qualitative and participatory methods, may elicit very different information and offer valuable insights. It was, therefore, felt that there is need to complement the quantitative, macro-level studies with qualitative, micro-level research into how participants experience and make meaning of HIV/AIDS at a local level within the education system (School of Education, Development and Training, 2004).

The research project was, therefore, lodged within a participatory research framework. However, the fact that this was a funded project placed constraints on the nature of participation by the community in the initial stage of the project. It was not possible to involve the community at the stage of writing the funding proposal and the research agenda was set by the group of researchers. Participation by the community occurred after the grant was awarded. In the ensuing stages of the project, a key element became the facilitation of ownership of the investigative process by local people. For example, a stakeholders’ forum and numerous community meetings were held
at which community members were consulted as local experts on various issues relating to the research process.

Further, in line with a participatory framework, visual methods and active representations of ideas enabled researchers to develop an in-depth understanding of local knowledge and to engage the local people in a process of reflection about their own lives. A range of participatory techniques was used to capture the voices of participants in the study, and to ensure rich qualitative data. These included individual interviews and focus group interviews with various participatory research techniques such as transect walks, vulnerability matrices, ranking exercises, aerial photograph analysis, photo-voice, social mapping, time lines, and Venn diagrams. However, there were various methodological challenges in the project related to the data production process. A key challenge was that the team comprised experienced researchers who were senior and junior staff in the faculty, and masters and PhD students – many of whom were novice researchers. A key consideration in selecting researchers for data production was the language issue. The majority of interviews were conducted in the local language, isiZulu. The research process, therefore, had to simultaneously involve planning the research process and data production, and the development of research facilitation skills and reflexive practice. This occurred through a range of training workshops. Although this process developed within a supportive research team that worked as a community of practice, the challenge of addressing inherent power imbalances was constantly reflected on, and it was conceded that these could not be fully resolved. Further tensions related to the context as researchers had to engage in diverse schools and educational settings; in diverse geographical locations; in different communities; and with diversity in terms of race, language, class, political affiliations, etc. (cf. Van der Riet, Hough and Killian, 2005).

Research strategy

The primary purpose of our study and focus of this article was to gain a clear sense of the participatory research processes used by a cohort of researchers working on the Richmond research project. More specifically, we attempted to understand how this group understood participatory research, to what extent the research they did was participatory, how notions of participatory research were embedded in the data they produced and what the inherent strengths, limitations and tensions were in the participatory methods they adopted.
We used purposive sampling and two criteria were used in the selection of our participants. Firstly, all seven participants were researchers from the University of KwaZulu-Natal working on a NRF funded project-exploring barriers to basic education in the context of HIV and AIDS. Secondly, all the participants were using participatory approaches to produce data. In using these two criteria, we had built up a sample that was satisfactory to our specific needs.

It was our desire to encourage intensive interviews where the participants were able to ‘dig deep’ and communicate their understanding and use of participatory methods. To facilitate this, we used a qualitative approach because it is well suited to gauge an in-depth understanding of the phenomenon under study. The primary instrument used for data production was in-depth interviewing. At the root of in-depth interviewing is an interest in understanding the experience of people and the meaning they make of that experience (Seidman, 1991). In-depth interviewing assumes that meanings, understandings, and interpretations cannot be standardised and, therefore, cannot be obtained with a formal, fixed choice questionnaire (Denzin, 1989). Open-ended questions were used during the interview process as this ensured a conversational dialogue between the researchers and participants. The conversational style of the interview process was further enhanced by the fact that both researchers and participants have been working together on the research project for a period of approximately eighteen months. All in-depth interviews were audio recorded and transcribed verbatim by a professional transcriber.

In addition to the data we gathered through in-depth interviewing of the seven researchers, we also drew examples from other data sets in the project that involved participants such as School Governing Body (SGB) members, volunteers working for an NGO, educators, and learners. These data sets were important bases of information as they gave us further insight into understanding how notions of participatory research are embedded in the data producing process.

In analysing the in-depth interviews and the content of the data sets, the purpose was to expand, refine, develop and illuminate a theoretical understanding of participatory methodologies used on a research project exploring HIV/AIDS as a barrier to learning. The analysis involved a cross-case analysis for the purpose of theorising from experiences drawn from the in-depth interviews and the various data sets.
Discussion

Knowledge and power

If the exercising of power produces what is held to be knowledge, what is the right interpretation of events, the valid act or utterance within that practice, possible ways of acting and limits of what can be done, then for the purposes of this article we question who has access to social discourses and what is possible to know? Certain possibilities of thought are constructed by those who have access to social discourses that produce knowledge in a particular context. Note how one of the researchers describes his experiences during an interview with the School Governing Body (SGB):

Well especially within SGBs there’s power dynamics that operate. The principal is the key person and often dominates the discussion.

(Researcher)

The principal is in a key position of access to social discourses both in terms of language and social positioning within the institution. Clearly access to participation in the dominant discourses of schooling goes beyond physical presence; issues of language, positioning and knowledge are crucial for the production of knowledge through discourse. Similarly, we question how researchers gained access to local knowledge and how the research process generated new knowledge for the participants. Evidence from the interview transcripts show that participants often play out a persona just for the satisfaction of play. For example, the aim of one of the focus sessions was to build rapport with learners. Note how the learners respond and indicate mimicry and superficiality to please the facilitator:

L: Me, I have thought. I liked the fact that we spoke about things that we do not like at school, like the toilets. We must help each other.

L: Me too I liked that.

L: Me, I liked that we must help each other.

V: Yes Smiley.

L: As we were playing and also we must help each other.

L: We must help each other and be kind to each other. (Grade 9 learners)

The above example may typify a shortcoming of focus group sessions and bring into question the extent to which focus groups de-individualise the
process and limit access to individual knowledge. The interpretation offered here offers a critique of focus group interviews and does not intend in any way to devalue the benefits from such sessions; for example, focus group sessions do enable the negotiation and construction of realities and identities during the course of talk and interaction where participants could achieve immense support especially when researching sensitive issues.

Most of the researchers working on the project were of a different social and sometimes racial positioning from the participants; in most cases epistemologies and world views differed significantly. An example from the educator data set:

Interviewer: Can I ask one burning question, how much respect do they have for the school, for themselves? Are they angry with themselves that they’re falling pregnant – are they angry with the school, angry with themselves

(Educator interview – interviewer is a researcher).

This is an example of how researchers have constructed their own realities around issues that may differ from participants’ accounts. This brings into question whether researchers are able to gain access to local knowledge. Researcher reflexivity around epistemologies in examples such as the above is crucial in the data production process. Many of the focus group sessions were drawn from the researchers’ project, especially in terms of the researcher’s social and institutional position. Similarly, the researcher developed the questions, directed the sessions, shut down discussion in the mastery of the participatory technique, closed down other possibilities of thought and other possibilities of truth and steered the session in particular ways. In many instances, the researchers were not involved in setting the agenda. Take for example, the following contextualisation of data of the educator group, gathered at one of the schools, where the researcher comments:

It was very frustrating trying to get a time, date and group together. Teachers are too busy with internal exams and matric. Also not very keen on the whole research activity (Educator group data, p.1) . . .this was a nightmare. Almost as bad as trying to collect data/materials. No one wanted to get involved; management was uncooperative and disinterested. Teachers were uncooperative and avoided being part of the research group.

(Researcher)

There were many instances where participants questioned the rewards and benefits for themselves or for learners.
Voice

One of the objectives of the research project as articulated in the project proposal submitted to the NRF was that

[t]here is little known about what is happening in classrooms or in the lives of the most vulnerable children. Exclusion will persist as long as children and their families are denied an effective voice in defining it and changing it. Action needs to build from their perspectives. There is a need to make analyses participatory.

(School of Education and Development, 2004)

But does participation alone give adequate voice? In seeking to involve participants in the research project, participation does not simply imply the mechanical application of a ‘technique’ or method, but should entail a constant process of dialogue, action, and analysis. Our observations from across the data sets indicated that not everyone participated equally in the focus group sessions, although some participants became more engaged in the prolonged processes over time. Some, however, remained silent throughout the process. If silences were voices, the research process would take a different course. Thus data production process becomes as much about who is excluded or who exclude themselves as who is included in the process. The data produced thus becomes the product of sounds, silences, conflict and struggles – some of which are not captured when the research process is approached in particular ways. We question whose voices are heard, whose voices are silenced by the social arrangements and what the silences in the participants’ accounts reveal. The researcher’s construction of children, particularly rural children, and the way in which their knowledge could be accessed raised questions about whether participants were given voice around issues of HIV/AIDS in a manner in which they could talk about it:

I’m talking specifically about rural children who are brought up in authoritarian households within a school environment which does not encourage convergent thinking. . . and I think we got some useful information without them being respectful, obedient, compliant, convergent, those things.

(Researcher)

Researchers, particularly in the learner group, struggled with giving voice to the participants on the one hand and maintaining discipline in the session on the other:
I mean, we were often caught up in that kind of struggle, how do you give people the voice in a controlled setting.

(Researcher)

This highlights the point made earlier about the extent to which focus group sessions de-individualise the process. How does one give voice to individuals in such a session?

**Situated ethics**

The Richmond research project aimed at obtaining a situated understanding of the impact of HIV/Aids as a barrier to basic education, and its intersection with other barriers experienced in a particular localised context. In examining ethical issues in the project, it has become evident that the issue of ethics cannot be in the traditional way as a set of general principles that can be applied across a range of contexts. Drawing from perspectives of Simon and Usher (2000), we see the need to question the notion of universal ethics, and to examine ethical acts and principles as they are situated and mediated in socio-political contexts. In other words, a situated ethics is local and specific to particular contexts and situations. Notions of scientific objectivity and value neutrality are therefore problematic. Any statements, such as the issue of informed consent, are mediated by the socio-political dynamics that are local and specific. Such a perspective challenges the actions and decisions of researchers. In the Richmond project, various ethical dilemmas and tensions emerged. Some of these will be examined from the perspective of the notion of situated ethics.

One of the reasons for the centrality of ethics to a discourse of emancipatory research is that such research is political and value critical. Johnston (2000, p.88) argues that ‘values must be unearthed, clarified, questioned’, and confronted at all levels. The issue here is how the knowledge claims made by the researcher relate to the researcher’s values. For example, one of the researchers (a lecturer and teacher educator at the university) whom we interviewed mentioned how she had to confront her own taken for granted assumptions about teachers and teaching in a rural context. Prior to her engagement in one of the focus groups with teachers, she had very strong and definite views that teachers working in a rural context should live in the community and immerse themselves in the community, and that the government’s imperative should make it mandatory that teachers move to and
live in the rural context in which they teach. She confronted her ‘academic’ assumptions when she engaged with the teacher journals in one of the project schools.

I certainly question some of my assumptions especially around the issue of teachers living on the (school) premises. There were some really poignant passages that some of the teachers had written about living out there. “I am so tired of smelling of paraffin and smoke.” It is not as simple as thinking the state may be looking at providing teacher houses and getting teachers out there. It is a much more complex issue.

(Researcher)

This researcher was moved by the fact that teachers in their journals had a lot to say about the rigours of living in cottages on the school’s premises. On a visit to the cottages, she realised that the conditions were difficult. Each teacher lived in one room that served as a bedroom and cooking area. Teachers also alluded to the fact that the community felt that they had ownership over the teachers, for example, demanding use of their cell phones. In her analysis, the researcher was also able to question the power relations embedded in situated contexts. Figueroa (2000) argues that in research facts should not be distorted to fit the value positions of the researcher as this would seriously undermine knowledge production. Such ethics must be based on contextual factors or else the marginal voices will be silenced.

Another ethical issue in the project emerges from the fact that the political context of the research can impose various limitations on the emancipatory goals of a research project. According to Johnston (2000), in participatory research, tensions between methodology and outcomes can present ethical dilemmas. In the Richmond project, it became evident that this tension surfaced. The issue relates to the overall situatedness of a funded research project that imposed certain limitations on the scope of the research and on the emancipatory aims of the project. The funded project was not a participatory action research project. In other words, there was to be no intervention that would lead to immediate social change. From the outset, researchers were honest about the project aims, and the aims of the research were made clear to participants at all levels in the community. However, many researchers felt caught in a tension between wishing to make a difference in terms of social change, and the feeling that they were adopting the stance of outsiders with their own self-serving agendas ‘doing research’ on people in the community. In other words, this created ethical dilemmas for researchers around the extent to which the research was exploitative in particular to a marginalised, rural
community. This issue was raised by a number of researchers, who were ideologically committed to emancipation and social justice, but who were faced with the constraints of the research methodology of a funded project.

We have found that ethics are inherent in the participatory techniques we used. To examine the tensions regarding what constitutes ethical practice when researching vulnerable people, we will refer to one of the techniques, photo-voice – an image based approach. Volunteers working for an NGO that runs a centre providing aid to families affected by HIV/Aids became participants in the research project. Using disposable cameras, the volunteers were requested to assist researchers in the project by mapping barriers to basic education as they experience these in the areas in which they worked. Once the photos were developed, the volunteers had to write about what the photographs depicted, and present the stories at a workshop. Many of the photographs represented the inside of homes, members of the family, and material resources. Below are two stories that emerged from this exercise:

This is the M. family, and this is granny and her grandchildren. These three grandchildren are orphans, their mother has passed away, and the father is in jail as we speak. The father was the councillor and people thought he was involved in killing people during violence and then he was sent behind bars. So the kids were left with the granny, and the granny is now too old in such a way that she can’t think properly, and at times, she talks nonsense and loses the pension money. The house is not that clean. Most of the times the kids come to eat here (at the centre) and we also give them food parcels.

(Volunteer working for NGO)

These children have no place to stay. They live in a deserted house. After the death of their parents, they went to stay at their granny’s house with their aunt. Their aunt gave them a hard time and asked them to leave the house. They found this deserted house and are living with their 22-year-old sister. The problem with the house they stay in is that it is falling apart. They do not have enough food but are doing well in school. Their sister is doing amatoho (part-time jobs), and supporting the boys and their schooling. They get food parcels from the centre, and at times they find themselves in poverty.

(Volunteer working for NGO)

These stories raise difficulties for the very basis of what we mean by ethical considerations in research. According to the researcher who worked with the volunteers, considerations of ethics involved conventional processes such as confidentially, informed consent, voluntary participation. However, questions arise about the impact of the socio-political contexts in which these were negotiated. What of the power relations that operate in contexts of vulnerability and marginalisation? How was access negotiated with those
photographed? How was permission obtained? Who were the ‘gatekeepers’, in other words, who were the arbiters of what to photograph and what not to photograph? On what grounds was permission obtained from the families? How was informed consent negotiated and what does it mean in this context? Were those photographed free of coercion or deception? Did they have the capacity and competence to consent? Did anyone refuse to be photographed or to have their private space invaded?

The issue of power is complex in the context of the use of photo-voice in view of the fact that the families depend on the centre run by the NGOs and the volunteers for social aid and support. Questions to ask are: Who owns the private spaces of the families? Was the assumption that there were no private spaces? What do we mean by ethics in a context of marginalisation and vulnerability?

These questions are political as they challenge issues of power. According to Usher and Simon (2000, p.5) “politics and ethics are inextricably entwined”. What is clearly evident is that a western, universal ethical framework is inadequate for a context of vulnerability, marginalisation, exclusion, powerlessness, and deprivation. Ethics needs to be engaged within socio-political dynamics that are local and specific. In other words, researchers need to analyse the particularities of mechanisms of power, that is, how power plays itself out in people’s lives in a concrete way.

**Emancipation**

All of the research participants constructed their responses as being stories of minor successes – showing their roles as researchers to be transformative and emancipatory. Each participant does this in a different way, to varying degrees. For example, six of the participants explicitly indicate their success by articulating how they have diluted the distinction between researcher and researched and contributed to the transformation of the groups they have been working. One prominent example of this is evident in the narrative of one of the participants who notes,

I think just the process of interviewing people about something like HIV/AIDS is often [. . .]: it gives people a chance to talk about things that they often don’t talk about. So to that extent it might help people to articulate and express things that they don’t talk about, so to that extent it might be transformative.

(Researcher)
Drawing from the transcripts generally and the example cited above, it is evident that the participants are aware of the transformative and emancipatory objectives of participatory research. A common argument that emerges from six of the seven participants is that the safe spaces (created through the participatory research process) which enabled the research participants to share stories and/or experiences were in themselves transformative.

\[T\]he more one shares... it helps healing and I think that the more we share the more we heal... I know that for myself... So I like to say that yes it was transformative... that by telling stories and by sharing about stories of pain and hurt in general can bring about change...  

(Researcher)

While not making explicit statements about emancipation the researcher participants seem content to believe that the sharing of experiences initiates the process of personal transformation and therefore liberation. Previously silent voices are now being heard resulting in the emergence of new social discourses. To what extent transformation occurs is difficult to measure or quantify, and therefore it makes good sense to explore the researched groups’ experience of the participatory research process.

Several possible reasons can account for the way the researchers assume that the research process is tranformatory and emancipatory. Our view is that the researchers make these assumptions because they have appropriated the research vocabulary on participatory research and participatory action research, and have mistakenly merged that understanding with that of participatory techniques. Secondly, they may perceive that what they say is what we (meta researchers) want to hear and thirdly, the researchers feel that the research process should have some outcome and, in this case, the outcome is emancipation.

**Researcher reflexivity**

Situated ethics in research foregrounds a commitment to researcher reflexivity which implies, firstly, making the values which infuse the research processes explicit, and secondly, constantly interrogating claims to what is knowledge. Johnston (2000, p.91) explains that it means “the possibility of decentring, of questioning our beliefs, our facts, our understandings, our theories, and of transcending our value commitments”. This means taking into account our situatedness as researchers, our frames of reference, our prior beliefs, and
presuppositions. Scheurich (1997) suggests the need for an ethics of constant questioning and interrogation of our ways of knowing as researchers. Researchers need to acknowledge their own location and position in the research, and how their own perspective can impact on the research process and outcomes. Scheurich (1997) points out that multiple positionalities and multiple locations make up the identity of the researcher.

In line with the above arguments, the perspective of situated ethics challenges the notion of observer neutral knowledge, and the belief that truth is independent of the researcher. Glen (2000) draws attention to the self and positionality of the researcher within the research process, and argues that the dynamics of research relationships influences the research. Therefore, researchers have to be self-reflexive. They need to analyse their own particular location and position in the research process.

One of the researchers in the project reflected on the experience he and researchers in the team had when interviewing staff at a well-resourced urban school. White teachers were in the majority at the school. The discussion was around HIV/Aids as a barrier to basic education.

[W]e found one of the participants – I think she was the only person who was not white – did not respond much, then left after ten minutes or so. Now that worried us a bit that she did not feel part of the group. That was the only occasion where we had educators not fully involved in this process. The power relations – I think we also had people from the SMT (School Management Team) – and we were talking about issues that appeared to be Black related. I thought that we were possibility not doing it the correct way. Then I felt she felt a bit uneasy and left. I mean this is my perception, I may be wrong.

(Researcher)

This researcher reflects on whether as researchers they, in fact, perpetuated inequality and dominance in this particular context, and marginalised a voice. Banister, Burman, Parker, Taylor and Tindall (1994, p.150) explain that this kind of reflexivity “centralises, rather than marginalises or denies, the influence of the researcher’s life experience on the research and on the construction of knowledge”. We believe that there will always be complexities in the position of the researcher. It is important to foreground ethical tensions embedded in the positionality of the researcher.

A further issue related to researcher reflexivity requires that cognisance must be taken of power differentials and inequalities of race, class, gender between researcher and researched. This relates to the issue of self and Other. In the
project, many researchers were conscious of their elitist, academic, privileged, middle class backgrounds that positioned them as outsiders. However, reflexivity requires a researcher to go beyond the binary positioning of self and Other. Usher (2000, p.33) argues for the need to “examine the hyphen at which self-Other join in the politics of everyday life and to work against inscribing the Other”. She explains that if our discourse is about those who have been ‘Othered’ or about ‘Othering’ we deny the hyphen. However, if we engage with the social struggles with those who have been oppressed and marginalised we work the hyphen. In an interview with teachers at a peri-urban high school, a researcher raised with teachers the issue of poverty and hunger in the area,

Interviewer: Just go back to the hunger story too. Are there children who are hungry because of negligent parents? In other words, they’ve got parents who don’t care for them. Because this is something we’ve picked up this … er there is a degree of … of parents. … who worry about other things TVs and their alcohol and so on while their children go hungry. Do you think that’s a problem?

Educator: I wouldn’t say they don’t care. because you’ll find that there are parents who really care for their own kids but the problem is they are unemployed. They don’t have their source. … the source of income themselves. It’s only the grandmother who is providing for them. … feeding about 6 or 7 kids in the family. So they do care, the problem is they do not have the source of income. And there are those who who. … who don’t care. … but ja. … I will say it’s about 5 per cent.

Interviewer: So it’s very few who don’t care.

(Educator interview, interviewer is researcher)

In this vignette various ethical questions arise. Is there a danger that we may pathologise the marginalised and inadvertently control the research process? Can the complex social and political processes in the lives of participants be understood by us, outsiders to the context? Is there a danger of perpetuating marginalisation when researching the vulnerable, and of making assumptions about how the participants see their worlds? Two issues need to be highlighted. First, as researchers we need to guard against imposing our own meanings on situations, and work to avoid reducing all groups to one identity. Social reality and human experience are too complex to be homogenised. Furthermore, knowledge is situational or perspectival, as explained by Lather (1991), and connected to social realities and power relations in those realities. Feminist researchers have stressed the heterogeneous experiences of people in
view of the fact that gender, race, social class and other relevant categories intersect in the concrete experiences that make up people’s lives.

If such an ethics based on contextual factors is not applied, there is the danger that vulnerable communities can be constructed as deviant. Usher (2000) calls for ‘critical conversations’ that are sensitive to and force into the open power dynamics. These conversations may not solve ethical problems in research but as Figueroa (2000) argues may engage researchers reflexively in questioning values, assumptions, evidence, and research procedures.

Conclusion

In this article, our analysis suggests that deconstruction is an ethical imperative in research critical to make explicit “the complexity, historical contingency and fragility of practices through which knowledge is produced” and the “indeterminacy and discontinuity in acts and processes of knowing, what is known, and who can be the knowers” (Usher, 2000, p.180). However, deconstruction does not aim to overthrow and replace existing research paradigms and traditions, but it calls for an interrogation of what kinds of research practices emerge from them. Deconstruction foregrounds the marginal and the silenced, and moves them to the centre of analysis by critiquing the notion of universal standards of research ethics believed to be necessary for ethical judgments. In addition, the outcome of participatory research may say as much about the researcher as the participants. Deconstruction places an obligation on researchers to think in alternate ways about the research process and the inherent contextual factors, and to become active in articulating tensions and complexities in ethical considerations. This is even more critical in the context of research on sensitive issues, particularly in the context of HIV and AIDS.
References


Notes

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