ABSTRACT

The HIV/AIDS pandemic is not only changing the world, it is changing the way in which we do research in and about the world we live in. This pandemic is challenging the ways in which we think about the world. In this paper we will discuss the ways in which this pandemic has influenced our research on children coping with HIV/AIDS in South Africa. HIV/AIDS defies linear intentionality in a research design and it provides no point from which it is possible to view comprehensively. Still, in this paper we attempt to signify particular tensions that have been part of our research process. They are tensions between 1) methods and theories, 2) developed and developing contexts, 3) crisis of representation and lived experience, 4) participation and observation, 5) moving from field to texts, and 6) authoring and de-authoring the processes of knowledge production. This research process has considerable challenges, but the benefits include new ways of understanding the representational and conceptual complexities involved in an inquiry process that focuses on a pandemic that defies our existing paradigmatic perspectives.

INTRODUCTION

In South Africa the worst of the HIV/AIDS pandemic is still ahead of us. Conference papers and research articles about HIV/AIDS in Southern Africa will often introduce the reader to the overwhelming statistics of infection rates, deaths, projections and the number of children who are affected by the disease. This type of knowledge is an important vehicle by which the urgency of our response to this pandemic can be conveyed. However, this is but one type of knowledge and it should not blind us to the real responsibility of constructing knowledge and social theory that goes beyond the numbers. This calls for the participation of scholars and intellectuals around the globe, to create situated knowledge that are relevant to the HIV/AIDS pandemic in their contexts.

Western ideologies and bio-medical research have dominated knowledge construction and theorizing about the pandemic. In South Africa there is a need for the construction of sound, compelling, social and educational theory that questions the supremacy of the dominant discourses of the pandemic. Treichler (1999: 234) states that the production of knowledge is
a fragmented enterprise by necessity, but that the "sequestration of culture from both scientific and social discourse has especially negative effects on international dialogue". She rightly states that statistical knowledge travels well, but cultural knowledge does not (Treichler, 1999:234). From this it may follow that participatory research from a poststructuralist perspective may make vital contributions to knowledge construction and theorizing about HIV/AIDS in South Africa, but also that the ways in which it is disseminated becomes equally important.

In this paper we will share the way in which we are doing research about the ways in which South African children that are infected and affected by HIV/AIDS are coping with it at the moment. The time (2001-2002) and place (urban and rural areas in South Africa) where this research is taking place is important, because of the impending ways in which this pandemic will be influencing the world we live in.

In describing this process we will be tapping into the burgeoning literature in the field of HIV/AIDS, but we will also be reverberating against the parameters that are set within the field of qualitative research, and particularly that of doing clinical participatory research within this field (Miller & Crabtree, 2000). The paper will start out by reflecting upon children who are coping with the HIV/AIDS pandemic in South Africa. We will provide a short synopsis of the study to date and we will share some of the research design parameters that are impacting on the study. Finally we will discuss the tensions that we have encountered while conducting this research.

CHILDREN COPING WITH THE HIV/AIDS PANDEMIC IN SOUTH AFRICA

Children choose from a range of coping strategies that are similar to coping strategies that are utilized by adults. They use self-protective behaviors and they regulate their thoughts, actions and emotions to protect themselves against stressors. However, children are not miniature adults and the ways in which they process stress and trauma is often more non-verbal than verbal. Their reactions may also often seem extreme because they are acting out, rather than "talking" out. In looking at coping in children these differences are important (Woznick & Goodheart, 2002:65). Silver (2001:22-24) points out that children react to stress by:

1. Internalizing stress: When children react with depression and/or anxiety to a stressor or trauma.
2. Externalizing stress: When children react to stress or trauma with disruptive behaviour, anger, clowning or passive dependancy.
3. Somatizing stress: When children develop abdominal cramps, stomachaches, headaches, diarrhea or frequent urination or bowel movements.

The theoretical framework for this study acknowledges this uniqueness and these differences and considers the fluidity of coping processes and strategies in children within the context of HIV/AIDS (Ebersöhn & Eloff, 2002).

Generic coping strategies can become complicated in coping with being infected and/or affected by HIV/AIDS. Coping strategies such as communicating and expressing emotions or maintaining a sense of personal worth is difficult if the adults in your life have died. A World Bank publication (2002) on Education and HIV/AIDS provides the following anecdote:

"She does not go to school any more. For one thing, her small, rural school has been disintegrating under the impact of HIV/AIDS: teachers, already in short supply, have been dying, feeling too ill to teach, or moving to the city to seek medical care. For another, her grandparents - newly charged with the grandchildren after losing their own son and
daughter-in-law to AIDS - have opted to spend their meager income on school fees for her two brothers, but not for her.

At age nine, she does not have HIV/AIDS, but she is growing up without parents, without an education, and without the knowledge or resources to guide her choices in life. Her future partners or future husband may well be HIV-positive. If so, she too, voiceless and powerless, will become infected. And if she lives long enough to have children, she will be unable to give them any better chance at life".

In this study we seek to understand the coping processes and strategies of children such as her. Planning a response to HIV/AIDS requires more precise information on the current and future numbers of children and orphans affected by HIV/AIDS (World Bank, 2002: 17), but we believe that planning a response also requires qualitative knowledge on the ways in which children such as her are coping. In doing so, we need to consider the unique coping processes in children, the impact of HIV/AIDS on their coping processes and the research process that seek to understand their coping.

We also need to understand the coping processes of children who may be living with an infected parent. A recent comparative US study by Reyland, McMahon, Higgins-Delassandro and Luthar (2002:313-329) indicated that children living with an HIV-seropositive mother cope with greater disturbance in the parent-child relationship, experiences less social support and show greater disturbance in psychological functioning, than that of a group of children in the same community that were not living with a parent who were HIV-seropositive. Secondary analysis of the multivariate findings indicated that the differences were characterized by perceptions of more hostility in the mother-child relationship, a perception of less social support and less self-esteem. Again, these findings point towards the need to understand the coping processes of children who are affected by HIV/AIDS. But will similar findings be true for South Africa?

In a study on Poverty, AIDS and children's schooling in 28 countries, Ainsworth and Filmer (2002) found considerable diversity between variables such as orphan status, household wealth and child school enrolment. These results were diverse to such an extent that they recommend country-specific studies before considering mitigation measures in terms of enrolment. Studies like this emphasize the importance of country-specific studies in the field of HIV/AIDS, because the variables are so diverse, that cross-site comparisons will be dangerous and probably misleading.

Thus, the rationale for this study: Exploring the coping processes of children in South Africa who are infected and affected by HIV/AIDS, by using a participatory clinical research design, that allows for a poststructural analysis of the data that is yielded in the study.

SYNOPSIS OF THE STUDY TO DATE

We will start the synopsis of this study by introducing the researchers in the study. We concur with Lincoln and Denzin (2000:1049) who state that qualitative researchers are not objective, authoritative, politically neutral observers standing outside or above the text. They are locally situated and historically positioned. The inquiry process is conceptualized as a collaborative, participatory process that joins the researcher and the researched in an ongoing moral dialogue. This makes us both vulnerable, but hopefully it also contributes towards the moral responsibility we bear as researchers, and towards the layeredness of the text that we share here.

We are both white Afrikaans women researchers. We are both married mothers of two children. We have both completed our pregraduate and postgraduate studies at South
African universities. We both grew up in apartheid South Africa and both rejoiced in the birth of the new democratic rainbow nation, that is now South Africa. We are both senior lecturers at the University of Pretoria - a formerly white university, which is currently undergoing transformational processes in terms of staff, students and structures. We are both registered educational psychologists. We share a love of children, teachers, academia and research. It is this, and other, factors of our historical and local situatedness that we bring to this research process.

We have come to do research on coping via slightly different paths: one doing research on stress and coping in the context of inclusive education and the other doing research on stress and coping in the context of lifeskills and emotional intelligence. Through collaboration on an early childhood intervention project and a concurrent shift in the research focus areas in our own Faculty of Education, the impact of the HIV/AIDS pandemic became more and more evident to both of us. Being educational psychologists our first inclination was to do research on interventions to help children to cope with HIV/AIDS. Until one day when someone casually asked us: But do you know how they are coping at the moment? A literature review revealed the obvious: the literature on children coping with HIV/AIDS was predominantly Westernized and/or quantitative. This study was born.

This study was conceptualized as a participatory clinical study that explores the coping processes of children who are infected and affected by HIV/AIDS in South Africa. We were of the opinion that a participatory study will provide us with data that may otherwise be inaccessible. We did not want to polarize complexity by creating dichotomies in understanding their coping processes. We wanted to create a multi-layered representation that will deepen our understanding of their existing coping processes. The impact of HIV/AIDS on children is both multifaceted and complex. They suffer psychological distress and increasing hardships due to HIV/AIDS (Unaids & Unicef, 2002:4). This we know. But how do we conduct a competent inquiry into this - even if we use participatory methods?

In a chapter on AIDS, Africa and Cultural theory Treichler (1999:208) identifies four obstacles of competent coverage of HIV/AIDS in Africa: the magnitude of the crisis, cultural differences, political obstacles and existing conventions about HIV/AIDS. Magnitude causes both exaggeration and downplaying. We believe that the same obstacles hold true for research on HIV/AIDS in Africa. The following quotation may illustrate the point (Treichler, 1999:209):

"Within the Eurocentric, biased, doomsday mode of reporting typical of Western AIDS coverage, afflicted African people appear as the passive recipients of internal and external help, while Africans at large are charged with failing to address the epidemic, even failing to be aware of it; [...] A very different view emerges in African publications, which catalogue multiple efforts to fight the epidemic by governments, women's organizations, church groups, school authorities, nongovernmental organizations, artists, prostitutes' groups, and so on".

In this study we wanted to represent South African children and their coping processes. We wanted to do this as South African researchers. Even though the differences between ourselves and the children we are researching are still vast, we believe that we share a historicity that is tied to the country where we all grew up in. We also believe that we bring a specific lens to the research process that may not be available to researchers from other countries that do the same research.

As data collection methods we are using multiple site visits, observations, interviews, play, photographic materials and child drawings. As data analysis methods we are drawing on the parallels that Miller & Crabtree (2000:619) draw between qualitative research processes and clinical processes. This process entails interpretive and reflexive processes that involve
description, organization, connection, legitimating and representation. This is what Miller & Crabtree (2000:615) calls opening up the clinical research space. According to them, the dominant biomedical model of research rests upon the following nine premises:

1. **Scientific rationality**
2. Emphasis on *individual autonomy*, rather than on family or community
3. The *body as a machine*
4. Mind/body *separation*
5. *Diseases as entities*
6. Patient as an *object* and the resultant alienation
7. Emphasis on the *visual*
8. Diagnosis and treatment from the *outside*

In this study we wish to move away from these premises with methods that "become a primary source for *hearing* [...] stories and their associated metaphors, *caring* in relationships, and resisting the colonizing narrative of institutionalized medicine. The study of bodies and their place in the production and expression of sickness and health becomes a core strategy for clinical research that enables the bridging of paradigms" (Miller & Crabtree, 2000:615).

### TENSIONS IN THE RESEARCH PROCESS

Moving away from the dominant biomedical model of research is a challenging endeavor. In this section we attempt to share some of these challenges by highlighting the tensions that have been part of this research process thus far. The fact that we signify six particular tensions may create the illusion that these tensions are separate constructs. However, we have found that they fold back and forth onto one another and create multiple layers of understanding. They are tensions between 1) methods and theories, 2) developed and developing contexts, 3) crisis of representation and lived experience, 4) participation and observation, 5) moving from field to texts, and 6) authoring and de-authoring the processes of knowledge production. Each one of these tensions will be explored by referring to the questions that arose during the process. By no means do we wish to create a "comfort text" (Ebersohn & Eloff, 2002; Lather & Smithies, 1997:51). We wish to rather create a text that leaves the reader with several diverse portals that lead towards a more complicated understanding of children coping with HIV/AIDS in South Africa and the research processes that may accompany it. It is a text that weaves stories of doing participatory clinical research, with the stories of children coping with HIV/AIDS in South Africa.

### Methods and theories

There is a multitude of ways in which we as researchers can report on and make sense of the data we gather of children coping with HIV/AIDS. We can focus on their coping. We can focus on their being children. We can focus on their orphanhood. We can focus on HIV/AIDS. We can focus on their South Africanness. We can try to create complex texts that layer these constructs in a way that can create new understandings. In the process we give meaning and we construct worlds - contributing to theory on children, coping and HIV/AIDS in South Africa. Yet, in seeking theory within HIV/AIDS Treichler (1999:144) rightly states that, "after more than a decade, we still do not know precisely what we know, whom we have reached, what they have learned, how they have changed". How do the methods we choose contribute towards the theory on children coping with HIV/AIDS in South Africa? How will the choice of other methods bring us to different conclusions?
In this study we remain starkly conscious of the intricacies that are embedded in the methods we choose and the theories that guide our methods. We cannot separate the methods from the theories, the politics of data gathering from the politics of data analysis, but there remains a tension that broadens our methods and enriches our theory. Lather (Lather & Smithies, 1997:196-197) refers to a refusal to contain AIDS in a familiar framework in their research, because it puts readers and writers at risk, for the fact that they are presumed to know about worlds that are presumed to be knowable. In our research, the search for unfamiliar frameworks and ways of knowledge construction provide the opportunity to challenge familiar frameworks, to identify constricted perspectives, to strengthen capacities and to be enriched by reciprocity in the research process.

**Developed and developing contexts**

In this paper this tension, though sparsely discussed here, will probably provide the most contentious portal towards "other" worlds. The definition of "developed" and "developing" contexts is influenced by culture, history and power interests. It is an important current debate. For the purpose of this paper, we will therefore, focus on what it means for us in this study.

In this study we spend weekends in rural communities where children gather wood for fires and carry water from far away because the adults are away at funerals. Then we go back to our lives in the city and at the university. We move between what seems to be different contexts. But who defines those "contexts"? Who decides which aspects of those "contexts" to focus on? If context is defined by history, what is the definition of a "context" in the here and now? If context is defined by power, where does the power lie in the research process? Do we decide how much, when and where we allocate power?

The HIV/AIDS pandemic is biological and biomedical, but it is also a cultural and linguistic pandemic (Levine, 1994; Treichler, 1999). As social scientists we contribute towards the cultural and linguistic growth of HIV/AIDS. This means that understanding the contexts we work in and questioning our assumptions about those contexts are necessary, if we are to understand its conceptual and representational complexities.

**Crisis of representation and lived experience**

We are two adult women researchers who are non HIV+, but we are attempting to tell the stories of children who are HIV+ or whose lives are hugely affected by HIV/AIDS. This creates tensions between representation and lived experience. The questions that we struggle with are: To what extent are we able to represent their lived experiences? Is what we observe to be their "lived experience", truly their "lived experience"? What happens when we are not there to visit, to observe, to interview, to play, to take photographs and to draw pictures with them?

The crisis of representation has been documented in the field of qualitative research (Denzin & Lincoln, 2000; Lather & Smithies, 1997), but for us this remains a challenge that is particularly daunting in the field of HIV/AIDS research in South Africa. We seek answers to representational, methodological and conceptual questions. We sometimes find answers, but then we start questioning the answers and we spiral upwards or downwards in seeking answers that will guide the process of representing what we find. Are we asking the right questions? Are we asking the right questions at the right time?
Participation and observation

As we move towards more participatory research designs, we also move towards uncertainty. We believe that we also move towards more authentic knowledge, while embracing the grayness of blurred distinctions between researchers and participants, participation and observation. Are we participating while we are observing? Are we observing while we are participating? The distinctions between “us and them”, researchers and participants, women and children, affected and infected, writers and storytellers, become less clear as time goes by.

Moving from field to texts

There is a comfort in and to a desk with open books, articles, research reports and a computer that awaits the written word. There is often discomfort or disequilibrium in moving between the worlds of books and the world of children coping with HIV/AIDS. There is discomfort in the process of attempting to capture the "reality" that is outside. Any written text, however detailed, will always remain but a small representation of the data that was collected and of what is considered to be the "field" of research in a particular study. There will always be omissions. There will always be decisions that are made while writing that leads to too much or too little time spent on aspects that may perhaps lead to a deeper understanding of the research problem. How do we decide what we write about? What influences those decisions? How do we account for the fact that the text will always remain a representation of a reality that may be vastly different from that which is represented in the text? How do we account for the reality that is created by the text we write?

Authoring and de-authoring the processes of knowledge production

In their research on women living with HIV/AIDS Lather & Smithies (1997:9) ask:

"Are we talking about these women? for them? with them? We should be uncomfortable with these issues of telling other people’s stories. [...] Part of me wants to begin sharing the stories we are hearing; part of me wants to move softly, with restraint, being careful not to pounce to quickly in thinking I understand their lives well enough to tell their stories to others".

In doing research on the ways in which children are coping with being affected and/or infected by HIV/AIDS in South Africa we are constantly treading the fine line between stories of despair, loss, tragedy and stories of hope, resilience and a remarkable sense of community. It is the same stories and it is different stories. As researchers, how do we tell these stories? Who are the authors of these stories? Can we draw distinctions between authors and participants? How do we protect the process of knowledge production from ourselves?

DO WE FIND A CONCLUSION?

The writing process during the last part of this paper was an uncomfortable process. Suddenly we were moving between headings, writing paragraphs here and adding sentences there - moving towards the end of the paper and then skipping back to add more under an earlier heading. We even found several incomplete sentences during this process of going back and forth within the text. This was not true for the first part of the paper. It happened during the process of exploring the tensions in the research process, and to a certain extent it came to be symbolic of exactly that which we wanted to share in this paper:
the uncertainty, the responsibility, the reflexivity and the changing nature of what it means to "create" knowledge while doing research in the field of children, coping and HIV/AIDS in South Africa.

**BIBLIOGRAPHY**


