

“The Ground Beneath Me”: Creative Vision, Youth and HIV/AIDS

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A Thesis

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ABSTRACT

“The Ground Beneath Me”: Youth, creative vision and AIDS

Shannon Walsh

HIV infection is a fast growing phenomenon amongst young people worldwide. In South Africa infection rates amongst youth are particularly high, and the need to find strategies to engage young people in issues around healthy sexuality are imperative. This research uses visual and ethnographic approaches as a method for engaged research that supports community led peer education; with young people building on their own lived experience as part of the process.

Borrowing from ideas of engaged pedagogy by bell hooks, Henry A. Giroux, and Paulo Friere and “thick and deep” data collection as explored by Clifford Geertz, Joseph Tobin and Claudia Mitchell, *The Ground Beneath Me* attempts to understand how to engage youth in creative strategies towards social change and more concentrated peer education around HIV/AIDS. This research is also influenced by understandings of AIDS in a global context through theorists such as Cindy Patton, Catherine Campbell, Paul Treichler and Paul Farmer amongst others.

Ultimately this was a qualitative, open-ended process, which looked at both the process and the final works as part of the data, and generated non-empirical results (including two video by-products and a text of youth authored writing and drawing). The findings indicated the need to include young people as change agents in creating health-enabling communities; to contextualize AIDS in terms of globalization, race, poverty, and stigma; to focus attention on gender-based violence and structural violence as risk factors; and, to keep gender issues at the forefront of youth education around HIV prevention.

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I would also like to acknowledge the generous spirit, patience and guidance shown to me by professor Claudia Mitchell, who inspired much of this work, but who also had faith in my abilities long before she had reason to. Her mentorship has greatly stimulated me intellectually, academically and personally.

DEDICATION

I dedicate this thesis to all the young people who participated in the projects discussed in this thesis. Without their enthusiasm and dedication, none of this would have been possible. I would also like to dedicate this work to Mandla Oliphant - a colleague, an activist, a friend and above all, a great inspiration to me.

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INTRODUCTION

I'm a Xerox of my former self... I am glass, clear empty glass...
I am a glass human disappearing in rain.

(Wojanrowicz, 1992 Untitled photomontage)

Why am I here?

The question that never gets asked, the question that lingers unspoken in workshop discussions, in conference presentations, in university hallways, in townships and glossy city streets where educators and facilitators shuffle outlines and learning units, the question that must somehow find its place in the work I am doing in this land so far away from my own is: Why are you here? This has been a self-reflexive project from its beginnings, and for me, the inquiry and explanation of the work I have undertaken starts with myself.

It would be unfair not to ask, repeatedly and honestly: What good does this do? Does it do any good at all? The statistics and faces loom around us. This is AIDS. This is the biggest crisis to hit Africa, perhaps the biggest single crisis to hit the modern world. We know this; I know this. To do nothing seems almost blasphemous, reprehensible, yet, at the same time, does this work really make a difference? I suppose the starkest and frankest answer I can give thus far is: I don't know. Not with total certainty. We look for clues, for evidence and results. Sometimes they present themselves, sometimes we dig them up and show them to the world, but, the statistics mount and we read each others reports on what went wrong and how to do it better next time more often than we'd like. Does it make sense for a white North American girl to fly halfway around the globe to South Africa to become part of a struggle that was not hers to begin with? Ultimately, for me the answer has been yes because

I do think this struggle is my struggle too, even if it is mainly because of the wealth, privilege and health I enjoy.

I am a white Canadian twenty-something young woman. I have more than average education. I was raised by a single working mother and lived a middle to lower-middle class life in London Ontario, a town I was quick to leave. I started traveling as soon as I was able to earn enough money to go. From early on I was emotionally affected by what I saw as injustice, mainly around race and class, largely due to reading books like Eldridge Cleaver's *Soul on Ice* at a young age. I understand, to a fair degree, the privilege I've had but I also understand that that knowledge only carries me so far. Here I am, in South Africa, working with underprivileged youth, trying, perhaps altruistically or naively to make some kind of positive contribution to the struggle I see around me here. I guess that's the short answer to why I'm here: the struggles here inspired me. The spirit and energy of people in South Africa to step up to their own challenges and to fight back startled me. The big blue South African sky folded around me and I fell in love. I fell in love with the kids and with the place and with the struggle.

It is not a solely academic endeavor. It is not an altruistic one either. Often it seems that in some way this work is part of my own evolving artistic practice. I am still digging around and trying to uncover what brought me here in the first place and what brings me back.

Authentic help means that all who are involved help each other mutually, growing together in the common effort to understand the reality which they seek to transform. Only through such praxis – in which those who help and those who are

being helped help each other simultaneously – can the act of helping become free from the distortion in which the helper dominates the helped.

(Paulo Freire 1970)

As Freire writes here and as Marianne Gronemeyer has eloquently written elsewhere, ‘help’ has many loaded connotations. Mine is ultimately not a project of ‘help’ but I hope a contribution to a better understanding of the realities that young people are facing around HIV/AIDS in South Africa and the means with which we can propose creative and collaborative solutions to fight the pandemic. It is important to acknowledge the problematics of working as a North American in the global South. I would agree with Gronemeyer when she comments “modern assistance is frankly calculating” and that “the metamorphosis from a colonialism that ‘takes’ to one that supposedly ‘gives’ has been completed under the protection of this euphonious word, help” (55). Throughout the work in South Africa I have tried to keep conscious of the fact that this ‘help’ could hurt, and to tread as lightly and as collaboratively as possible. In Chapter Four, when I discuss in more detail the field work with the young people in Cape Town, I have tried to keep an eye to how the research project’s intervention could intervene as little as possible, or in as positive a way as possible. It is not an easy task but it is critically important. Any work undertaken in the majority world must also keep a solid perspective on the forces of globalization, corporate politics and minority world agendas, which are often imperialist and bent on maintaining dominant power structures.

To do this, I take Gronemeyer’s and other’s advice. She states, “the sole helpful intervention would be to confront and resist the cynical wielders of power and the profiteers

in one's own home country" (66). With this in mind, I devote Chapter Two to looking at how international trade policy, which Canada is very much a part of, seriously affects and undermines many of our attempts to abate the growing death toll in Africa.

Of course I was in South Africa to attempt to share something of what I know how to do, but mostly I have tried to learn, collaborate, and create. I was also in South Africa to spread around a little of what my privilege affords me: time, resources and the means to be heard. Some of these resources, if given with few or no strings attached, I hope can actually be put to beneficial use.

The *Ground Beneath Me: Youth, creative vision and AIDS* project seeks to explore models for understanding how to engage youth in creative strategies towards social change, specifically around HIV/AIDS. While this is only one aspect of a bigger puzzle that includes community participation, geo-politics, access to health and education services and addressing inequalities of wealth and gender, creating spaces that youth can use to engage honestly and critically with these issues must be central to the ultimate projects of large-scale social change.

The research I will discuss in this thesis was primarily concerned with engaging South African young people in practical arts-based work around HIV/AIDS. I explored ideas around *arts-informed social change* as a method for engaged, activist research and change. I was investigating how action based participatory methodology could involve youth as actors both in telling their own experiences of HIV/AIDS in their lives, and by contributing to the overall strategies in HIV prevention education and AIDS awareness in their communities.

In the chapters that follow I will discuss the theoretical underpinnings of the work I have been doing, the context in which it finds itself, and the actual creative process undertaken with a group of South African youth I have been involved with over the past three years.

While my key focus here is on how arts-based participatory research can provoke youth towards deeper and more meaningful relationships around HIV/AIDS, I also hope to look at this project as an example of how *arts-informed social change* can be a form social activism and engaged pedagogy.

To begin with, I would like to map out an overview of the various projects that I will discuss in this thesis. Each of these projects happened over a trajectory of time that began with the *Soft Cover* project, directed by Claudia Mitchell, in early 2002, and finished with the *FACING the Truth* project in April 2004. An overview of the projects and activities that I frame my fieldwork around in this thesis include:

1. The *Soft Cover* research project, directed by Claudia Mitchell. I worked as a Research Assistant on this project to begin with and soon became a project facilitator and coordinator. Within *Soft Cover* there were a few activities conducted that I discuss in this thesis:

- a) Symposium *Getting the Word Out* involving youth, healthcare workers, academics, filmmakers, artists and youth workers. This project also included six-weeks of hand-made bookmaking sessions that I was acting as coordinator and facilitator on.

b) *In My Life* writing workshop followed up this first project a number of months later and was facilitated by a renowned South African writing teacher.

c) The *Fire & Hope* video with and about youth activists that I directed and edited that included youth we had been working with in the *Soft Cover* project is also discussed. This video was the final product of the one-year *Soft Cover* initiative. (see Appendix A)

All of the above projects were done under the guidance and direction of Claudia Mitchell. I will also talk about two follow-up projects I completed on my own in 2003/2004. They are:

2. Atlantis follow-up with the Student Representative Council, writing and drawing workshop with youth from Atlantis at their high school
3. Khayelitsha follow-up with the *FACING the Truth* collective, which included video making workshops, which cumulated in the youth-authored video *F.A.T.T.* (Appendix A)

Throughout all these projects a South African facilitator/coordinator and I worked with a group of male and female youth aged 14-19, from Khayelitsha, Atlantis and Cape Town, South Africa. The various projects all focused on using the arts to get young people involved in activism and provoking a deeper commitment to issues around HIV/AIDS. While different activities were undertaken that I will discuss in more detail in the following chapters, overall the work was a type of research-intervention or research as social change that endeavored to engage young people in HIV prevention more fully while also collecting research on their responses.

During this action-oriented process, I collected data from our group meetings, the actual visual and textual work the young people created, and their discussions around HIV/AIDS. One of the goals of my research was to develop a broader, deeper and more complex view of the various issues that are at play in the lives of young people in South Africa and the impacts of those factors on HIV prevention. At the same time, I was also interested in exploring how teaching processes, research methods, and HIV prevention tactics had been used to positive and negative effects elsewhere. Because of my particular perspective as a filmmaker, and because of my use of video ethnography, production and viewing in my sessions, I was also interested in looking at how film and video contributed to our work in the field.

The principal goals of the research were often action oriented, and included:

- Engaging youth as activists and producers around HIV and AIDS issues;
- Promoting self-awareness and confidence in young people and to ignite a “chain reaction” of youth as peer educators;
- Educating participants on gender issues and sensitivities;
- Encouraging the use of arts as a means of social development and intervention;
- Effecting positive change in the sexual practices of the participants.

My goals were also to uncover and elucidate youth perspectives on HIV/AIDS that could advance research but also to engage youth in research as social change. In this way I was concerned with working with youth in South Africa to develop a participatory framework for research on sexuality and HIV/AIDS; to inquire around the ways young people would like to talk to their peers and community about HIV/AIDS; to add to current

research on youth, AIDS and arts-informed research; and finally to understand the current situation in HIV prevention work with youth.

As you will read in the chapters that follow, I attempted to address each of the goals with the involvement of the youth I was working with. The project often teetered between 'research' and 'development', and it was necessary to do some revision and self-examination while in the field given some unforeseen problems that arose, such as sustainability, which are not often an aspect of traditional research. I will deal with those implications and the way the project addressed them in more detail in Chapter Four.

This tension was also felt between the production of the materials from the workshops (the videos, writing and drawing) and the process of producing those materials. This became a methodological issue, which I will take up more in the section on methodology in Chapter one. Ultimately, the data overlaps at times between what the young people made, what they said about what they made, my field notes of the process of making and my impressions of the products. These of course were further complicated by the showing of work to other people and including it, for example, in this thesis, where it can again be transformed and revisited as another layer of data is created. These are complex methodological issues, which I do not fully attempt to answer in this thesis, but which, nonetheless, remain an aspect of how arts-based methods such as these will be investigated.

CHAPTER ONE

The Ground Beneath Me: Theoretical and Methodological Frameworks

CHAPTER ONE

To situate the studies that will follow in the proceeding chapters, I would like to underline some of the theoretical frames or conceptual orientations that guided the process in the field. These include discussions of AIDS globally that, to me, are inherent to any current study of the pandemic.

While much of the reading I have done informed this work, I will focus on five particular theoretical frameworks here:

- 1) Cindy Patton's notion of *thoughtstyles* and the tropical model of disease
- 2) The concept of Social Capital as discussed by Catherine Campbell
- 3) The social construction of Gender as a critical aspect of HIV/AIDS
- 4) Engaged Pedagogy or 'education as the practice of freedom'
- 5) Arts-informed approaches to social change

Theoretical Framework: Inquiring AIDS

There are multiple frames that rest one upon another in any inquiry into the AIDS pandemic. Paula Treichler (1999) voiced the first, and perhaps hardest, when she wrote *How to have theory in an epidemic?* In the midst of such a terrible and traumatic virus, how do we take the time out to talk and write about theory? As epidemic has become pandemic we seem to be asking ourselves, How to *use* theory in a pandemic – how to make theory accessible to

those who need it – and how to continue work on the ground in the absence of practical theory? Theory, it seems, has become more important than we ever thought it could be, as the pandemic grows unabated in many contexts.

As bell hooks (1994) writes, “Theory is not inherently healing, liberatory, or revolutionary. It fulfills this function only when we ask that it do so and direct our theorizing to this end.” (61) In the midst of the AIDS crisis, we must demand of our theory that it leads us somewhere healing, liberatory, and revolutionary. This remains for me a key aspect of the way in which I engage myself when theorizing AIDS in this project.

As I will discuss below, in the case of such theorists as Cindy Patton (1990, 1994, 1996, 1999, 2002) and Catherine Campbell (2003), critical observation has created a space from which we hope to better equip ourselves to deal with HIV/AIDS. With the complexities of AIDS, it seems that every step of the way leads us through a labyrinth of meaning, problems, human fallibility and crisis. Both Campbell and Patton, who I draw on extensively, also allow us space to reflect on our own failures and begin to build ways for us to move forward.

Perhaps the second framework most relevant to this inquiry concerns my own positioning, something I have also discussed in the introduction, as well as the cultural underpinnings of the way AIDS has been manufactured globally. I am writing as a North American about the AIDS crisis in South Africa. Given my particular political and cultural standpoint, I draw upon Cindy Patton’s writings in *Globalizing AIDS* (2002) to understand how AIDS has moved geographically as well as how its multiple meanings and metaphors have also shifted. The way AIDS has been politically constructed across geographic borders

must be an element in how we understand and discuss it. These constructions have not only affected cultural theory. I would agree with Patton that they have also affected individual, local, national and supra or international understandings of AIDS.

“Thoughtstyles”: Race, class, gender

Our task now is to reconsider what it means to think in terms of community, nation, and globe and to understand who can be empowered by such concepts and who will be excluded.

(Patton 2002, xxv)

My investigation into how arts-informed social change interacts with social activism must be seen in the context of the way AIDS has been constructed globally. These constructions are important to acknowledge since they affect very real aspects of people’s lived experience: from funding for governments and NGOs, to the kinds of messages that make it into the public sphere, and the way those messages are targeted at different social groups and at different geo-political regions. These larger frames affect the way information and programs trickle down to the community level, and it is critical to acknowledge how they have been developed and maintained.

I am interested in responses to AIDS and the form activism around AIDS has taken through the lens of what Patton calls ‘thoughtstyles’ based on the concepts of Ludwig Fleck (1977). Patton (2002) argues that the global AIDS epidemic has been mapped onto the world through discourses, or thoughtstyles, she separates as epidemiological and, more

recently, tropical. Patton suggests that the epidemiological discourse (or map) that has informed the way we understood and discussed AIDS in its first phase in North America has been replaced in the second and third phases of the epidemic with a tropical model of disease. This tropical model is rooted in colonial and imperialist understandings of the 'other' in the developing world and finds its origins in early tropical medicine. The current construction of this frame for looking at AIDS, she argues, has emerged through the World Health Organization and other international bodies, and has allowed for a separation between 'us' (over here) and 'them' (over there).

While epidemiological distinctions that used risk categories to define and separate reinforced decades of homophobic, racist and sexist responses to the epidemic, tropical thoughtstyles allow the African epidemic to be seen as different from what was experienced in North America. Epidemiology told us there were risk groups: the public was separated and classified in relation to their relative 'risky-ness' – if you were a drug user, a sex worker, a Haitian or a man having sex with men then you were at risk. As the epidemic changed and grew, Patton (2002) argues that the way we discuss and represent the virus also changed. This new tropical model, based on colonial understanding of tropical Medicine, separates the pandemic geographically, i.e. some regions have AIDS, others do not. The tropical model is best clarified if we think about how diseases such as Malaria are understood globally – mapped out and sectioned off region to region. As Patton writes, these distinctions greatly effect how we grapple with AIDS:

Epidemiology's risk groups produced flawed policy by making it possible for those avoiding prevention messages to say, 'I'm not one of those.' The tropical model

allows an equally disastrous ignoring of prevention advice: 'I don't live/go there'.

(120)

For global AIDS work, an awareness of the tropical model is useful for examining how various theorists have written about AIDS in their own contexts and, in this case, the context of South Africa. Investigating these models is also a way to keep in check the potential racist underpinnings of "African AIDS" that has permeated much of the minority world or Northern writing on the subject. In fact, it is often Patton who I return to in order to investigate the way that racist assumptions inform ways that we construct prevention, view activism in the South, and understand how and why we give donor aid. It is important for me, as a scholar and activist straddling these two worlds (my Northern-ness and my commitment to South Africa) to interrogate my own positioning throughout the work I am doing for this thesis, as well as the broader work I am undertaking to do in the country.

For example, as "Dennis Altman and many other gay, social commentators quite rightly reject the attempts to blame male homosexuals for the AIDS epidemic. However, they accept, uncritically, suggestions that AIDS originated in Africa" (Dada 1990). I think it is important to see how these continual racist undercurrents have marked the construction of African bodies. This does not only inform the way North Americans theorized *about* Africans, but given the political nature of globalization, it also informs the way programs are administered, the kind of messages that are applied to the African context, and the overall approach of Western aid to the South.

In another example, Robin Gorna's text *Vamps, Virgins and Victims* that is primarily concerned with women and AIDS, uncritically asserts that, "the striking shift in the 1990s has been the prevalence of HIV among populations with 'heterosexual' contacts outside the UK...characterized as an African connection"(Gorna 1996, 100). This kind of discourse underlies many of the theories and assumptions about the so-called African epidemic.

The infrastructure of disparity and oppression (homophobic, racist, sexist, and classist), which has marked AIDS since its beginning is underscored by an international context in which "the rich get health, and the poor are seen as expendable" (Patton 2002, 31). On this global stage, marked by the tropical frame of disease, the individual is but a small player. Strategic alliances with governments are implicitly necessary, as are our alliances with communities and individuals if the epidemic is ever going to be grappled with successfully.

Community focused HIV prevention strategies

In South Africa, there is often an implicit understanding of the fact that social capital must be strengthened in order to deal with AIDS effectively. Some of the most current AIDS methodology puts community at the center of prevention initiatives¹.

Catherine Campbell (2003) presents a framework that allows for an intersection between individual and community interests and needs. In *Letting them Die* she investigates the Summertown Project, a HIV prevention project in a mining town in South Africa "designed

¹ See for example work in the Faculty of Education at the University of Kwa-Zulu Natal, such as the *Seeing for Ourselves* research team headed by Naydene de Lange.

in a way that sought to view HIV-transmission as a community problem rather than simply as an individual problem” (37). Her ideas inform my own ideas about prevention initiatives and present a strategy for tackling AIDS that focuses on notions of community, or common good. She takes up the tropical African AIDS model and confronts it head on, outlining a framework for dealing with what she sees as four interlinked concepts critical to combating AIDS. They are: social identity, empowerment and critical consciousness, social capital, and power.

[This model] seeks to understand the transmission and prevention of HIV not as a problem ‘out there in the townships’ or as the product of reified exotic African behaviours or cultural practices, but as a social issue located at the interfaces of a range of constituencies with competing actions and interests. These include not only those local communities, organizations and individuals directly affected by the epidemic, but also local and national political leaders and business groups, overseas experts and international development and funding agencies (8).

This multi-dimensional approach to prevention is one in which politics and ‘critical consciousness’ play a key function. It is not as though this type of model is absent totally in North America, but even when models like this are used (see Tolman 2003) it is often still with a larger portion of the weight placed on individual behaviour models that have proven themselves to be ineffective. (Douglas Crimp who became HIV positive after decades of AIDS activism is a startling example of this). As Campbell says, “one study after another – as well as rocketing AIDS statistics – has shown that people often knowingly engage in sexual behaviours that places their health at risk.” In North America both Leo Bersani and Douglas

Crimp, amongst others, have made this case: “sex as constitutively masochistic, potentially ego-shattering, opposed to self-mastery” (Crimp 2002, 269).

To elucidate Campbell’s (2003) theories more fully, I’d like to define each of the four concepts she has outlined for effective prevention campaigns.

A community member’s **Social identity** is “constantly constructed and reconstructed from one moment to the next.” This identity includes memberships in social groups (such as those constructed through occupations) to those positions mediated by factors such as “gender, ethnicity or socio-economic position”(Campbell, 47). Each of us has a social identity that is mediated by these various factors. Campbell implores us to factor ‘social identity’ into how we approach individuals and communities.

Empowerment and critical consciousness: In this frame Campbell has drawn on Paulo Freire’s notion of critical consciousness (which I take up below in the engaged pedagogy section). Campbell problematizes a simplistic notion of ‘empowerment’ and looks at it from a broad perspective that includes power and positioning. Ultimately she seeks to stimulate the “development of insight into the ways in which social relations, particularly gender relations constructed within conditions of poverty, undermine the likelihood of good sexual health”(51). Critical consciousness implies that members of the community will have access to information and be in a position to use that information actively.

The concept of **Social capital** has been at the center of many debates on how to create a health-enabling community. Principally, social capital as Campbell understands it implies that,

people are most likely to undergo health-enhancing behaviour change if they live in communities that offer high levels of participation in local networks and organizations, which are associated with increased levels of trust, reciprocal help and support, and a positive local community identity (51).

Central to social capital is the idea that members of the community need to feel that their “views are respected and valued”, and that “they have channels to participate in making decisions in the context of family, school and neighbourhood”(51). Campbell points out that while social capital is important, it has been hotly contested and must be critically examined. Social capital itself might “serve as a source of social exclusion and disadvantage, in contexts where opportunities for creating, sustaining and accessing beneficial social capital are constrained by poverty, or other forms of social inequality, such as caste or gender.” So, then, social capital is a useful concept, but one that needs to be critically understood and examined.

Campbell also argues that **power** must be an aspect of the framework, since people’s participation in HIV prevention, or any other initiative, can be greatly affected by their particular social situation. She argues that, “Social change through participation can be properly understood only if one understands the ambiguity of power relations and the double-edged nature of power” (55). She indicates that it is here where social scientists have

a role to play in unpacking how power works in relation to participation in public health strategies.

For *The Ground Beneath Me* project, these four concepts guided how I came to think about the work with the youth participants. While my project here has been small, the ways in which any and every prevention campaign can contribute to some of the above strategies must be considered. When designing the project and while in the field, I was aware of how community players interacted with the youth; the level of individual ‘critical consciousness’, and ways to strengthen it; the various power dynamics at play – from my own power in the group context to that of members of the team; and finally, how social capital in the various contexts added to or took away from the work we were doing. In Chapter Four I will talk more about the findings related to these concepts, and in the Conclusion I will make some recommendations that take this framework into consideration.

This focus on community and society-informed prevention strategies is remarkably different from the context of North America, in which the individual never lost his/her illusory control over the ability or inability to be safe. In fact, the politics of blame that defined most of the struggles waged by North American activists over the years was never entirely shaken. The moralism of this position is one that Douglas Crimp (2002) takes the North to task for as he reveals his seroconversion:

...the moralizing is, in fact, a psychic defense [against the fantasy of absolute safety]...if even the educated, rational, and responsible among us can become infected with HIV; if AIDS activists and prevention educators can seroconvert now,

then we have to think differently, with still greater complexity and self-understanding, about protection. We have to think about the force of our own unconscious, of our terrible vulnerability, of the fact that we, too, are human. And we have to accept the possibility, even the inevitability, that some of us will fail (300).

Could African bodies, too, fail in our North American conception of them? Are they continually failing? How does our moralizing translate in the tropical thoughtstyle? Perhaps these questions are less significant to African theorists and activists, who may have not assumed the “fantasy of absolute safety” given the trepidatious and turbulent position that they must constantly live within. At the same time, some of the young people in the study were also shaken by the fact that mentors and AIDS educators could seroconvert after having worked in prevention for many years. As a young women in our discussion group, Nosububiso, remarked in the transcripts:

Nos: The [educators] are clever and they are becoming stupid. They are doing what they shouldn't do. I don't know what they think they will get out of it.

This again reinforces the notion that community inclusion, stakeholder responsibility and Campbell's (2003) concepts of social capital must be integrated into effective prevention strategies.

It is interesting that in spite of this long standing theorizing, even novel approaches to prevention, such as Tolman, Stiepe and Harmon's (2003) work which places young people in concentric circles of gender constructions, still place the most weight on the individual to

make change. In a sense, perhaps Campbell's notion of social capital here could be useful to understand how in a context of high social capital (like North America) the individual does become more important.

In her section on "why such a commitment to individualistic perspectives"(8-9) Campbell concurs with existing arguments that point out how the role of psychologists and theorists in the developing world have turned our attention too far away "from the social change that needs to take place to support the likelihood of healthier sexual behaviours", and she argues for a move "towards more participatory approaches...such as community-led peer education and collaborative stakeholder partnerships that seek to promote community contexts that enable and support behaviour change" (9). Campbell calls for a deeper understanding and commitment to a health-enabling community (11).

Gender: Social Aspects of AIDS

Why is gender an HIV/AIDS issue? Gender refers to the social constructions that define the roles women and men are expected to fulfill in a given culture. While gender roles and norms change from culture to culture, in most parts of the world, men tend to have greater social, political and cultural power and privilege. As I demonstrate below, gender roles have an impact of HIV vulnerability for a number of reasons for both young women and young men. Young women are specifically more vulnerable to HIV due to gender imbalances.

Young women's vulnerability and risk

Increasingly, as we see in other areas of globalization, women have become the most burdened part of society in relation to HIV and AIDS². As the virus has spread into heterosexual populations in Africa, Asia and South America, women's particular vulnerability has become extenuated. Young women are one of the most vulnerable populations worldwide to HIV infection (UNAIDS). Female biological and epidemiological vulnerability to infection, combined with gender imbalances (Holland et al 1999 & 1992; Roth & Hogan, 1998), economic dependence, ideas of femininity (DeOliviera 2000), structural violence, rape (Larkin 2000) and other factors all add to HIV rates in women continually climbing. The UNAIDS report indicates that women represent 55 percent of all people with HIV/AIDS in Africa. As Cathie Albertyn notes, "people with HIV/AIDS are not only more likely to be women; they are more likely to be poor, African women"(Albertyn np, 2000). For the purposes of my study, understanding and integrating gender issues into the overall structure of the project was a necessity.

Young women are physically more vulnerable to HIV infection than young men because of a number of factors, including the following:

- The increased likelihood of tissue tearing during intercourse facilitates HIV infection.
- STIs are harder to recognize in women than men, and having an STI makes it easier to contract HIV.
- There is more surface area on the female genital tract than on male's.
- There is a higher concentration of HIV in semen than in vaginal secretions.
- More semen is exchanged during sex than vaginal fluid.

² See for example the themed issue of *Canadian Woman's Studies* on Women and HIV/AIDS, Vol 21 (2) 2001 for an extended discussion of these issues.

While physical factors are very important aspects of young women's vulnerability, I was interested in understanding more deeply some of the social and cultural factors that contribute to female vulnerability. Wilson and Msimang (2002) argue that the primary cause of young women's vulnerability to HIV comes from unequal gender relations and social norms.

Sexual violence and rape presents a very real threat for women and girls to contract HIV (Larkin 2000). Gender imbalances and dominating relationships can make it almost impossible for young women to negotiate condom use. In countries like South Africa where there is a high incidence of sexual violence in schools and communities, and where the national AIDS prevalence rate is at 22.8% with infection rates rising at an alarming pace, the situation for women is particularly grim (Human Rights Watch 2001). Young women in South Africa are 3 to 4 more times likely to become infected with HIV than their male counterparts (ibid).

As I discovered in my fieldwork, sexual violence and rape are a very real part of the cultural landscape for girls. The violence that has underpinned post-apartheid South Africa continues to add to HIV infections. The Human Rights Watch report *Scared at School: Sexual violence against girls in South African schools* (2001) indicates that, "although girls in South Africa have better access to school than many of their counterparts in other sub-Saharan African states, they are confronted with levels of sexual violence and sexual harassment in schools that impede their access to education on equal terms with male students" (np, 2001). If the school system is the primary means for young women to gain knowledge about safe sex practices, its often hostile and dangerous environment seriously hampers girl's abilities to navigate positive sexual practices.

Girls also face the serious threat of rape arising from cultural myths, such as the myth that purports that by having sex with a virgin, AIDS will be cured. Stories are told of many young girls and women who have suffered rape arising from this myth. One story featured in a 1999 article “In South Africa, doctors, courts fight brutal AIDS cure” by Charlyne Hunter-Gault reported that a two year-old girl was treated for rape in Addington Children’s Hospital in Durban. She has since tested HIV-positive and is developing full-blown AIDS. Three years later, the story of a nine-month old baby’s gang rape shocked the entire world. South African children are the tragic victims of gender-based violence leading to HIV infection.

While young men are often encouraged to have multiple sexual partners, young women are expected to be ‘innocent’ when it comes to sex. This makes it harder for women to talk about safe sexual practices with their partners, who might classify them as ‘sluts’ for bringing up the conversation. Because in society men often have more power in social relations, young women are also vulnerable to being coerced into having sex before they are ready (Wilson and Msimang 2002; UNFPA 2001; UNAIDS 2002).

A study conducted by UNAIDS (2002) found that young women globally are getting infected earlier and dying younger than young men. This appears to stem from the fact older (possibly infected) men are seeking sexual relationships with younger (more than likely uninfected) women:

Young women have consistently been found to have higher prevalence rates of HIV infection than men of the same age group. The assumption that this results from women having sex with older men suggests a possible inter-generational driver of the infection from men to women (5-6).

The prevalence of open discussion about males' sexual desire in the absence of discussion about females' desire can leave girls in a position where they may not feel that they have a right to insist on condom use. Women may feel that their sexual needs are inferior to their male partners and that the pleasure he enjoys (from not using a condom) is more important than her own safety (Lewis 1999; De Oliveira 2000).

In many impoverished communities, transactional sex is also common, whether sex is used in lieu of taxi fare, or if actual cash is exchanging hands and women are working in the sex trade (Msimang, 2002). There are many reasons that women may be unable or unwilling to negotiate condom use on their own behalf that have been explored by researchers, such as: an unclear perception of risky behaviour (De Oliveira 2000; Kumar, Larkin and Mitchell 2001); fear of rejection and/or emotional or physical violence from partner (Kumar, Larkin and Mitchell 2001); self-image of women as either "virgins or whores" (Lewis 1996); boredom/ apathy about safe sex (Mitchell and Smith 2002); and a dismissal of HIV and AIDS as not my problem (Patton 1996; Treichler 1988). Almost all of these propositions have been significantly explored in the literature around HIV infection and prevention. For all of these reasons and more, the vulnerability of women and girls to AIDS cannot be understated.

Young men's vulnerability and risk

Gender norms also affect young men's vulnerability to HIV/AIDS (Morell 2001; Pattman 2003). Young men are often expected to be knowledgeable about sex and so they don't feel comfortable asking questions about how to protect themselves. Gender roles also expect men to have many sexual partners that put them at greater risk of HIV infection. Young men are also expected to use drugs and alcohol and lead a more 'carefree' risky lifestyle (Steps for the Future 2003).

Young men who have sex with other men may also be afraid of discrimination and stigma from being open about their sexual practices. This can make it difficult to reach these young men with prevention messages, and may also limit their access to clinics and information networks. (Steps for the Future 2003) Further discussion of masculinity and its effects on young men can be found in (Frosh et al 2001), Pattman (2004), Morell (1998, 2001), Waugh (1999, 2000), and Gardiner (2001).

Based on all the above factors, prevention strategies must integrate discussion and awareness of gender issues. Throughout my fieldwork in South Africa, there was a continual focus on gender dynamics – both in the lives of the participants and in the group itself. Many of the participants claimed later that this was an important aspect of what they learned during the sessions, but it was also clear from the group dynamics and discussion that there is still a long way to go in terms of comprehending gender imbalances. Boys still tended to dominate group discussions that were mixed gender, and girls continued to keep quiet about their own opinions and the sexual violence they were subjected to on a daily basis. As time

went on and the group became more comfortable with one another, more open discussion began to take place, which was encouraging. Ultimately, adequate integration of gender issues into HIV/AIDS prevention strategies and educational contexts will be something to continue to fight for and work hard to establish. I will talk more about the gendered dynamics of the fieldwork in Chapter Four.

Engaged Pedagogy: “To educate as the practice of freedom”

My commitment to engaged pedagogy is an expression of political activism.

(hooks 1994, 203)

bell hooks (1994) explains a version of ‘engaged pedagogy’ that the work I have been involved with in South Africa attempts to reflect and learn from. I continue to believe that, as hooks says, education can be the practice of freedom. I would add to that to say that an engaged pedagogy can also inform an active, critical consciousness. It is my own personal desire and thrust towards active engagement and the belief that collaboratory research and education can get us there that brought me to this work. I rely a great deal on hooks, Giroux and Freire’s (1970) notion of engaged pedagogy to understand how and why I was doing ‘research as social change’.

Doing HIV prevention research in a traditional mode just could not be enough. Counting numbers, taking polls and inferring statistics while people are constantly dying is hard to justify. Creating research that is also action oriented and education based, on the other hand, is also challenging. It was not always easy to see where research began or ended.

Sometimes, it seemed the best plan of action was to step back and let the participants take the process over completely, which I did. At the same time, collecting traditional data at that point proved difficult. The things I might be looking for might not be the things that the young participants felt they needed in their lives or communities to make positive change. So the research, through this approach, had to accept being shaped by the agenda of the researched. Since I have a commitment to feminist research practices, this felt like the right thing to do. Researchers have argued convincingly that this is responsible social research. Watching the kids take the process over and integrate it into their lives has convinced me of the same thing.

...it was Freire's insistence that education create strategies for what he called 'conscientization' in the classroom. Translating that term to critical awareness and engagement, I entered the classrooms with the conviction that it was crucial for me and every other student to be an active participant, not a passive consumer.

(hooks 1994, 14)

Research, in my project, also became a form of engaged education. In this most current phase of research (see Chapter Four and Six) every participant became an active participant in the process. Relying on hooks, Giroux and Freire's concepts of engaged pedagogy, as well as Catherine Campbell's ideas about participatory HIV prevention programs led the research and the strategies I employed.

Methodologies³

In terms of research methodology, I have focused on a few scholars to inform my approach. Clifford Geertz (1974)⁴ and recent applications by Joseph Tobin and Claudia Mitchell have incorporated the notion of “thick and deep” data collection (Mitchell and Walsh 2004) in which special attention has been paid to each line of transcript, or in this case, the visual texts themselves. Geertz describes how thick description relays the deeper meaning attached to the actions and discourses of a given subject. For Geertz, delving deeper into meaning of words and actions of the research subject is the “object of ethnography”(7). Tom Barone also discusses “thick” descriptions in his writing on arts-based inquiry. He maintains “ ‘thick’ literary description grounds writing in a particular context so that the complexities adhering to a unique event, character, and/or setting may be adequately rendered.” (2004, np) Along with Claudia Mitchell, I would like to argue for deep readings of the life stories and realities that young people bring to the work on HIV/AIDS so as to better understand the kind of prevention strategies that make sense in a given context (2004). I will discuss the approach to “thick and deep” data collection and provide examples within my writing in more detail throughout the thesis.

³ There is a long history of conventional and feminist forms of interviewing that I would like to briefly touch on here. It is imperative to keep the obvious power differentials in sight in terms of a white Canadian woman interviewing black township men and women. Of course the data I collected was shaped and affected by the interplay of race and power in the South African context. While trying to keep these power dynamics in mind, I have tried not to bog down the transcripts with interpretive analysis. At the same time, I ask the reader to be aware these power dynamics while reading the interview transcripts. For more detailed accounts of interviewing, see Ellis and Berger 2003; Gary Fine 1994; Michelle Fine 1994; Strauss and Corbin 1990; Gitlin 1994; Holland et al 1992; Aggleton et al 1997, 2000; Rubin and Rubin 1995; and, Babbie and Benaquisto 2002.

⁴ Geertz was actually influenced by Gilbert Ryle’s notion of “thick description” and built his understanding of ethnographic anthropological “thick description” on Ryle’s earlier observations.

Arts-Informed Social Change

Another core aspect of my methodology is what I have been calling *Arts-informed social change*. What is meant by *Arts-informed social change*? While I dedicate part of Chapter Four and Six to further exploring this concept, I would like to explain it here. As a working definition, arts-informed social change can be understood as:

An action-based method in which artistic forms are used as a vehicle towards collaboration and engagement in social issues.

For this project, I was interested in how arts practices could be used as a methodology to revamp youth engagement with issues around HIV/AIDS. Arts-based methods have real potential in involving young people in social issues. Even a superficial examination of alternative forms of media where youth are involved provides a possible arena for discussion of prevention strategies. A quick survey of alternative youth culture leads us to spoken word, graffiti, Hip-hop, photography, rave culture, comics, literature, 'zines, kwaito and dancing. The efforts to bring together elements of youth culture and HIV prevention in South Africa by organizations such as Steps for the Future, Bush Radio, Soul City, Lovelife and DramAide, amongst others, contributed to enlivening the out-of-date, didactic prevention campaigns. Arts-based methods allow researchers to engage young people much more tangibly in the research itself through involving them in their own creative process.

For example, hip-hop culture (graffiti, DJing, break dancing and rapping) has long been a place in which young people have felt their issues are addressed. As Davey D points out in

his essay on the “History of Hip-Hop”:

Hip-hop continues to be a direct response to an older generation's rejection of the values and needs of young people. Initially all of hip-hop's major facets were forms of self-expression. The driving force behind all these activities was people's desire to be seen and heard (2001, np).

By speaking to youth within their own cultural norms and allowing them to make use of these methods to talk about the issues they face in their lives, messages take on a different tone and value. In Cape Town Bush Radio's dynamic campaign HIV-Hop, now renamed the Alkemy project, uses hip-hop to spread positive education and messages around HIV/AIDS and other social issues.

Photography and video has also been used as a methodology to involve young people in engaged pedagogy as evidenced by work such as Wendy Ewald's (1985, 1992, 1996, 2000) work with children in the US, J. Hubbard's (1994) work with native youth in *Shooting Back from the Reservation*, Linda Wong's (1999) *Shootback: Photos by Kids from the Nairobi Slums*, Montreal's *Project L.O.V.E.* with perpetrators and victims of violent crime, and Ricki Goldman-Segall's (1998) work with children and video, amongst many others.

Not only are arts-based methods useful in engaging young people, but the arts have also been a site of a great deal of dialogue around AIDS throughout the world. South Africa is rich in examples of ways in which artistic practice has been integrated into a dialogue around HIV/AIDS. A small sampling of recent work could include: Kauffman and Martin's (2003)

AIDS Art/ South Africa; Jonathan Morgan and the Bambanani Women's Group's (2003) *Long Life: Positive HIV stories*; Monkeybiz's (2003) *Positively HIV+: HIV & AIDS education through Beadwork*; the *Positive Lives* (2001) exhibition at the South African National Gallery and the work of Sue Williamson, Gideon Mendel, David Goldblatt, Clive van den Berg, among many others.

Scholarly work also has an emergent tradition of integrating visual methodologies with qualitative, action-based work. Interestingly there is a significant amount of this work that deals specifically with illness, death and body. In these areas, I've drawn on the work of scholars such as Ross Gray's performance based work with women and breast cancer (Gray et al, 2001); Ardra Cole and Maura McIntyre's work on Alzheimer's Disease (2002) in which they create texts and exhibition that invites the viewer into further dialogue on the subject of Alzheimer's; Sandra Weber and Claudia Mitchell's work on teacher identity and dress (1995, 2004) and visual inquiry (2004); and Jo Spence's photographic inquiry through self-portraiture and reflexive writing around her fight with breast cancer (1988, 1995).

Within visual studies and arts-based research, John Collier and Malcolm Collier have been long time proponents of visual methods. Their work in 1986 adopted a realist understanding of the use of visual images in research and advocated visual methods that would act as a support for the researcher. The idea that visual methods are less valid if subjective decisions are made (such as moving the camera or making editing or framing choices) has been an item of much debate since. Collier and Collier's more systematic and scientific approach to visual methodology does not allow for the richness and variance that visual data can provide, nor the visual as text in and of itself. John Prosser's edited work on *Image-Based Research*

(1998) and his work as part of the Visual Studies journal also looks at how image-based research can form an objective and catalogued index to compliment social research. At times problematic, Prosser's work sits within the work of more cautious social scientists who were aware and answering to the ongoing skepticism felt about visual images that were found not to be scientifically objective and therefore only useful as a compliment to texts or research rather than autonomous phenomenon in themselves.

On the other end of the spectrum, Tom Barone and Elliot Eisner's (2000) work on "Arts-based Educational Research" and Barone's collected essays in *Aesthetics, Politics, and Educational Inquiry* (2000), provide arguments "for writing that inspires and persuades a seemingly indifferent public" about school transformation, "curriculum-in-use", educational theory and inquiry often through the use of arts-based methodology (2000, viii). They see arts-based forms of qualitative research as a way to broaden the epistemological fields of traditional social science research. For them, arts-based educational research "is meant to enhance perspectives pertaining to certain human activities" and "is defined by the presence of certain aesthetic qualities or design elements that infuse the inquiry process and the research 'text'." (2004, np) They see this type of methodology as less concerned with concrete empirical facts and certainties than with broadened and deepened discussions and perspectives around education. In general, their work has revolved around literary forms such as life histories, poetry, fiction and so on, though not to the exclusion of other forms of arts-based practices.

Barone's work strives to create an educational framework that will contribute to the cultivation of the "strong poet", that is, "someone who refuses to accept as useful the

descriptions of her life written by others. Instead, the strong poet is a strong storyteller, continuously revising her life strong in the light of her own experience and imagination” (2000, x).

Sarah Pink (2001), who I rely on extensively in Chapter six, understands visual ethnography in “relation to a reflexive approach to ethnography that focuses on subjectivity, creativity and self-consciousness” (Pink 2001, 14). Her own anthropological work with photography during her research on female bullfighters in Spain provides numerous examples, amongst other things, of how the process of making visual images, and the process of looking at images once out of the field, can transform the meaning we make of them. In this way researchers are working with the data as both phenomena and method. Images, she argues, carry a certain amount of cultural and social weight and are part of the way people often describe the world around them. She takes photographs or video images herself, but also looks at how informants sometimes pepper their life stories with memorable photographs they show to her during the ethnographic process.

The anthropologists Marcus Banks and Howard Morphy (1997) propose rethink visual anthropology into a broader form than it’s sub-discipline in sociological anthropology has seen it. For them visual anthropology as a method “is in the first instance a flag, a reminder that much that is observable, much that can be learned about a culture can be recorded most effectively and comprehensively through film, photography or by drawing.” (Banks and Morphy 1997, 14) They see two main strands of visual anthropology as being “visual recordings and material products of culture”(14). At the same time as they discuss the indexing possibilities for visual material, they also allow for a broad range of interpretations

on how the visual might fit in to the anthropological project, including phenomena such as rock engraving, sign language, sculpture and dance.

Norman Denzin's in-depth work also provides another way arts-based practices can inform qualitative research projects. His own work on preformed ethnography and cinematic society (1994, 2003), and his work with Yvonne Lincoln on qualitative research methodology have informed some of my thinking about how qualitative research has multiple dimensions and applications. Margot Ely et al's (1991) work *Doing Qualitative Research: Circles within Circles* reminds us how qualitative research extends over multiple areas including "entering, observing, interviewing, analysing, reporting and reflecting."

Anthropologist Jay Ruby (2000) has also had significant impact on the field of visual methodologies. In his 2000 book *Picturing Culture: Explorations of Film & Anthropology*, Ruby argues for an anthropological cinema that is reflexive and aware of its ethics, reception and subjects. He believes that viewers need to be taught to see cinematic images within visual anthropology for their ability to transmit ethnographic knowledge. In his opinion, much in opposition to Barone and Eisner, these films need not be "good" works of art to communicate knowledge and viewers must learn to see them as such.

For a deeper discussion of qualitative research and on the ways in which arts-based approaches might also be used, see also researchers such as Michael Ball and Gregory W.H. Smith, Emmison and Smith (2000), Janice Jipson and Nicolas Paley's (1997) *Daredevil Research*, Carl Bagley and Mary-Beth Cancienne's work on qualitative research (2002), and Gillian Rose's (2001) clarifications in *Visual Methodologies*.

What much of this work points to is an idea of research as social change where data are both something one collects, but also something which re-enters the world and potentially transforms it. Michael Schratz and Rob Walker's work on *Research as social change* has also been very instrumental in the development of my understanding of methodology (1995). Schratz and Walker discuss the practical application of research as social change. They define action research as,

...concerned with improvement and change, with achieving now what otherwise might remain unrealized...ethnography is useful in the context of change precisely because it identifies what remains unchanged, it looks behind surface appearances to continuities and consistencies that might at first be hidden. (1995, 75)

This idea of research as social change, when married with thick and deep descriptions has greatly informed the way I approached my fieldwork. For Schratz and Walker, research should be an engaged, social/political activity. As they remind us, "research itself is essentially a social activity, not somehow removed from and outside social life" and that "theory extends our capacity to see alternatives, reminding us of the lost opportunities we create with every action we take and every word we speak. Its concern is not simply to say why the world is as it is but to provide us with space to think how it could be different." (125)

Tom Barone, too, in his approaches to arts-based educational research and his writing about education has defined research and education as a potentially socially engaged

activity and calls for “socially committed literature” from within the academy to strive towards transformation (2000). He urges those within the academy to speak out as clearly as possible to all of the society, “not from a distance, not through texts that need translation by intermediaries, but directly and compellingly so that the public ceases to imagine teachers and school kids as essentially negligent and malevolent characters in need of externally imposed discipline, and begins to understand the nature of the unfortunate culture and institutional forces that impinge upon their lives.” (2000, xv) This, seen in relation to the struggle towards relevant HIV prevention strategies, seems all the more relevant and necessary. For Barone, passionate and evocative writing could ignite social change and liberate research from the stasis of the academy.

I have also drawn guidance from Chris Argyris and Donald Schon’s (1974, 1980) ideas on ‘theories of action’ and action research. Specifically, they have influenced action based research practices in organizational and individual context through unpacking of the gap between one’s *theory-in-use* and one’s *espoused theory*. A person’s *espoused theory* is the theory about the world that she will give when questioned, the words she uses, or the way she would like others to see her. Her *theory-in-use* is what she actually acts upon, the things she does in her life, the ways she resolves conflict, the way she positions herself in the world.

For example, in a situation where a girl is being sexually harassed in a public place, such as being touched or kissed, at times her *theory in use* might be to give in to the harasser enough so that he would be appeased and she could safely get away. On the other hand, her *espoused theory* about what girls should do in similar situations might be to ‘just say no’. We can begin to unpack, through the concepts of *espoused theory* and *theory-in-use*, the way that girls

are dealing with the sexual violence that surrounds them on a daily basis. The gap between the two doesn't need to be negative, but it is important to understand it and factor it in to our discussions in order to bring about positive change.

This concept guided my thinking about how to read into the comments, discussion and visual data from my participants (their *espoused theory*) as well as their actual actions over time (*theory-in-use*). While my opportunity to observe their theory-in-use was more limited, the distinction was useful to me in terms of understanding how the often pat answers we get in regard to questions about HIV and AIDS can be problematized both inside and outside of the group context.

Argyris and Schon also present critical ideas about learning styles – single and double-loop learning, which have been used primarily in relation to organizational development systems. In the double-loop concept, learning occurs when an error is detected and corrected in ways that address an individual's (or organization- in this case community's) underlying concepts, beliefs and norms. In Chapter Six I discuss more about the tensions between young people's *theory-in-use* and *espoused theory*.

Finally I also make use of Brown and Gilligan's (1992) *Listening Guide* approach to reading the transcript data when I discuss gender in Chapter Five. Brown and Gilligan's *Listening Guide* encourages researchers to look back over transcripts and to read in the various levels of meaning that social and political contexts might bring forth. I am also drawing on Holland et al's (1992) ideas about working with transcripts and personal

accounts given by young women and how these need to be situated into a larger context that also includes the various researcher's perspectives.

Ethics

Ethics was a major and complex concern throughout this research. Various non-traditional issues were at play, which made keeping total confidentiality difficult if not impossible at times. I will briefly describe the approach I used within this work and discuss some of the ethical problems that arose during the fieldwork around the use of video imagery and real names in published texts. Very few of the various activities undertaken here fit into a confidential anonymous data gathering method that is used in traditional empirical sociology. Working in an interdisciplinary mode allowed me to think across disciplines and be creative in my application of ethical principles given the context in which I was working. In general I used a fairly standard ethical consent form for all my participants at the beginning of each phase of the project, but as is shown below, those consent forms alone did not always allow for the kind of work we were doing to take place, so new principles sometimes needed to be formed.

I was guided in my thinking about ethics by my understanding of traditional sociological practices, by my work in education with Claudia Mitchell and by my understanding of the implication of work around HIV/AIDS in South Africa and its culture of 'breaking the silence'. In fact anonymity itself became problematic in a context where speaking out publicly about AIDS was an act of resistance and activism. For many of the youth in the group who chose to do the writing and video workshops, their identification was part of what lent the work they made an activist edge and further enabled them as educators in

their communities. To ask them to remain anonymous would, in some of these cases, impede their ability to be spokespeople for a very taboo subject. 'Breaking the silence' around HIV and AIDS in order to destigmatize the disease is a large movement both within the government of South Africa and civil society and it was clear that some of the research as social change I was doing had a role to play within that discourse.

At the same time, ethical tension was not alleviated. While the participants in the video *Fire & Hope* signed traditional releases used for film consent and we discussed the implication of being seen on camera, it remained the case that the participants were still young people who may not entirely know the implications the video might have. Even I do not know, once in the public domain, the effects the video might have on the participant's lives or on the subject of HIV/AIDS. We discussed these issues in the group, but for the participants, it was far more important to contribute to the fight against HIV and to educate their peers than it was to remain anonymous. Again, the interdisciplinarity of the project came into play as I became much more the filmmaker and editor of *Fire & Hope*, which serves as an autonomous work in itself, than as a researcher in the traditional sense. In turn the video gained a life far beyond the fields of traditional academic research. It has played in schools, in community centres, at film festivals and even at the IV International AIDS conference in Bangkok. I am still getting reports of places the subjects of *Fire & Hope* have screened the video and the impact they feel it is having in their community.

In the *FATT* video, the project as far as I saw it was much less mine to control ethically since it was a project initiated, conceived of, and filmed by the participants. While we discussed ethical issues as a group and I obtained permission to bring copies of the video

home to use as part of my research, the original tapes remained with the group to use as they saw fit. They were able in many ways to exploit the research process, with my encouragement, to create something relevant to their lives. This was a very challenging process for me. For example, the group chose to ask their subjects on camera “Are you sexually active?” For me, this line of questioning tread over an ethical line that I had set for myself when working with young people, but the work this group was doing was not for the academy, and ultimately, what they needed out of it, and what they felt their community needed out of it, guided decisions they made in that sphere. Again we discussed ethical issues at this point and they revised the ethical consent forms that I had brought with me to suite their needs and which explained their project to the learners, parents, teachers and principals. Before the camera rolled they discussed the project with their subjects and made sure the subjects knew they were under no obligation to answer any of the questions if they chose not to. They also informed their subjects beforehand that they would ask some questions about personal sexual practices. Ultimately, their argument was that other young people needed to hear and see the realities found in their communities so as to be better prepared to deal with HIV and AIDS.

Within the book of writing *In My Life* an interesting ethical problem arose during our conversations for the project evaluation. A few young men talked about how being a published author who was identified had given them a certain social status in their community. There were a number of unforeseen benefits of this, including being better able to do HIV prevention peer education because they were held in esteem by other youth. At the same time, some of the young women discussed how they received some unwanted attention from men in the community who now saw them as celebrities. These incidents

were often uncomfortable and aggressive. At the same time, they agreed that they would not prefer to have a reprint of the book that was anonymous, since they were also enjoying increased status that aided them in their peer education work and had even provided unforeseen opportunities, such as being invited to participate in more events on the topic of HIV/AIDS. I take up some of their comments again in Chapter four, but from the above, one can see how the ethical considerations for this type of interdisciplinary work are varied and complex.

In other areas of the projects, such as group discussions, standard consent forms were used and anonymity maintained. In this thesis I retained real names for those who had consented to do so through the public nature of their writing or their video work. For everyone else who participated in the project I have changed names to protect anonymity. I have also changed names for quotations from video material that was not used in the final output that was approved by the group.

Since this work is action based in nature and endeavors to reach beyond the traditional research paradigm, ethical considerations have been a constant preoccupation and not easily resolved. To provide real tools for the young people in the project to walk away with meant that some difficult, and not necessarily foolproof, decisions had to be made. Each situation posed different problems and I have tried to address each situation keeping in mind the overall goals of the research that included finding practical ways to address the ever-increasing levels of HIV infection amongst youth. The idea that the research context itself and the researcher's decisions in the field might also guide the ethics process, rather than a

standard ethical procedure established before even heading into the field, was something that increasingly seemed applicable to this type of research I was doing. As Sarah Pink notes:

..the issue of ethics in ethnographic work refers to more than simply the ethical conduct of the researcher. Rather, it demands that ethnographers develop an understanding of the ethical context(s) in which they work, a reflexive approach to their own ethical beliefs, and a critical approach to the idea that *one* ethical code of conduct could be hierarchically superior to all others. (37)

While by no means do I feel that I have sufficiently unearthed all the ethical dilemmas that a project like this one proposes, by using a reflexive approach and discussing with those I was researching about (and with) in the course of the work enhanced my understanding of the complexities and difficulties that one must necessarily encounter in doing this kind of research.

Again I was struck by Pink's concepts around ethical practices that include giving something back to those being researched, or better yet, collaborating with the research subjects to create research that is useful to their lives.

Rather than the researcher being the active party who both extracts data and gives something else back, in this model both researcher and informant invest in, and are rewarded by, the project. Recent work in video and photography shows how these media can be used to develop very successful collaborative projects (44).

For the work I was doing in South Africa, the model described above felt the most relevant and applicable given the situation of the AIDS pandemic in the country. So then, were the ethical considerations complicated and extended, but so too, were the rewards both for me and, I hope, for the research participants.

Summary

In summary, I have outlined the five main theoretical frameworks that guide this work; Cindy Patton's notion of *thoughtstyles* and the tropical model of disease; the concept of Social Capital as discussed by Catherine Campbell; the social construction of Gender as a critical aspect of HIV/AIDS; and idea of Engaged Pedagogy or "education as the practice of freedom"; and finally an understanding of arts-informed approaches to social change. These five theoretical frameworks have been my guides in the field.

CHAPTER TWO AIDS in South Africa: A cultural pandemic

CHAPTER Two

Why AIDS? Why South Africa? In this chapter

I will discuss the context of AIDS in South Africa in terms of the rates of infection and the way globalization and civil society have shaped the debates around AIDS. South Africa has a history of youth

activism and arts based resistance and an explosive rate of HIV infection. Civil society has been effective thus far in South Africa, and this may be another entry point into strategies for successful arts development around HIV/AIDS. I explore this topic here because I feel it is important to situate the local activism that I was attempting to tap into and facilitate with youth in the larger picture of HIV/AIDS activism in South Africa. When I started working with these particular young people in South Africa I quickly realized that many of them had been working with the Treatment Action Campaign (TAC) in their communities. The engagement I found in the youth reflected a greater overall engagement with the topic of AIDS and treatment in the country that was fuelled by groups like TAC. This chapter provides some background on AIDS in South Africa and the activism that is happening within the communities I have been working. It is this commitment with critical rights issues on which my fieldwork attempted to build upon and for that reason I feel it is vital to dwell upon it here.

An important lesson to be learned from a study of the representation of AIDS is that the messages most likely to reach their destination are messages already there.

(Bersani 1987, 5)

The optic of globalization should ensure that we no longer fall into the trap of thinking that anything is any longer 'local' (Whiteside& Barnett 2002, 306)

Over the last twenty years, HIV and AIDS have defined our relationships with each other and with the world around us. AIDS has brought to the fore the various intersections of our identities, our communities, our politics and our power. AIDS is a global virus, both in the way it has spread over continents and geographical boundaries through infected bodies, and in the way in which the agendas of multi-nationals, corporations, governments and NGOs have formed and re-framed our dialogues around the pandemic. Worldwide, over 20 million people have already died of AIDS since 1981 and 5 million new infections occurred just last year, 3.5 million of which were in Sub-Saharan Africa (UNAIDS 2002). That brings the number of people who have been infected in Sub-Saharan Africa to 28.5 million.

HIV prevention initiatives involving youth are key priorities for South Africa that my fieldwork was attempting to address. Contributions to tackle the mounting AIDS crisis are important and timely. UNAIDS has identified youth, and especially young women, to be the most vulnerable populations in need of development initiatives around HIV/AIDS (2002). While there are many grassroots and governmental organizations working to curb infection and deal with the crisis, new strategies are in high demand. USAID South Africa has

developed a plan of action with the South African government calling for more research and projects aimed at youth and young women in relation to HIV prevention.

My decision to work in South Africa on HIV/AIDS issues was shaped by some of these factors. HIV prevalence rates in South Africa are some of the highest in the world at 22.8% (UNAIDS 2002), and there is a high incidence of sexual violence in schools and communities (Human Rights Watch 2001). Infection rates are rising particularly amongst young people. Many will not live to see their thirtieth birthday (UNAIDS/WHO 2000, 13). In the Report on the Global HIV/AIDS Epidemic UNAIDS and WHO states that the majority of new infections are in young people between the ages of 15 and 24, sometimes younger.

Globalized Politics

In South Africa, activists concerned with AIDS are dealing with the racist legacy of apartheid, globalization, and the politics of colonial oppression while much of the country lives in poverty. To give a snapshot of what is concerning African theorists, I think Alan Whiteside and Tony Barnett's 2002 text *AIDS in the 21st century* is interesting. With the tone of pragmatic economists, Whiteside and Barnett argue that we must factor health into a scheme of 'public goods' and get serious about tackling the global structural policies that help keep the epidemic growing. They are concerned with situating health and well being as a human right, but also as 'public goods' necessary to keep countries like South Africa afloat. They argue that these public goods must be protected by collective action and organization –

a global civil society – which is what many of the South African theorists write about and take to the streets to ensure.

South African theorists also tend to take the issue of individual responsibility to task:

We must turn away from the excessive individualism of the final decades of the twentieth century to a recognition...of the ways in which our individuality depends upon common undertakings for the common good (Whiteside and Barnette 2002, 348).

Of course AIDS must be defined and discussed in the context of globalization and the emerging political realities that grip the globe for a number of reasons. First, AIDS presents us with a stark example of the persistent divisions between those who have and those who have not on the global stage. The virus itself is a location in which we can clearly see how widening global divisions are affecting the powerless in societies around the world. Agreements like the Trade-Related Aspects of Intellectual Property Rights (TRIPS), imposed through the WTO, are at the centre of a raging debate around the way that Northern interests, mostly economic, threaten human rights worldwide.

As Douglas Crimp argued:

“Community Values” are, in fact, just what we need, but they must be the values of our actual communities, not those of some abstract universalized community that does not and cannot exist (Crimp 2002, 76).

While community seemed to define the way that constructions and battlegrounds formed around AIDS in North America, identity politics and community constructions that valued the same configurations of identity as found in North America were rare to be found in Africa. As Patton (2002) suggests, “the conflation of ACT UP actions and poststructural cultural criticism romanticized Third World countries. Supposedly overwhelmed by the harsh practicalities of their physical environments or backward governments, countries outside the European and North American contexts were imaged as not needing the luxury of transnational or sexual politics” (Patton, 25). While Patton may be right here, it is interesting that given the chance to associate and bring forward North American models of activism, key activist groups in South Africa like TAC have stuck firmly to a political agenda that is rooted in racial, colonial and economic oppression. Drugs and treatment in this context are not only difficult to get, they are actually denied by the hegemonic world structures and institutions that value trade over health.

In this chapter I focus on the relationship that globalization and international agreements has on HIV/AIDS treatment and the way the language of rights is being used by civil society in South Africa to challenge these inequalities head on. In order to better understand the pandemic in its South African context and why youth activism is critical within that space, we must understand the facts about rates of infection, vulnerability and so on, but we must also understand the implications of globalization on the way the virus manifests in South Africa. All of these factors will also shape my discussion of the fieldwork I undertook in South Africa and how youth activism fits into the larger scheme of HIV/AIDS work in the country.

I will explore the example of the Treatment Action Campaign's (TAC) efforts in South Africa to challenge international trade agreements and large pharmaceutical corporations to be accountable to the rising deaths of Africans with AIDS on account of the economic inaccessibility of life saving anti-retroviral medications. Focusing on the 2001 case with the Pharmaceutical Manufacturers Association (PMA) in South Africa, I will also highlight how the relationship between the state and civil society is now shifting in an effort to consolidate arguments against the emergent 'third party': non-state players. How this reforming of social and international relationships will ultimately alter the modern and post-modern world remains to be seen. While the fight for access to treatment has shifted remarkably in the years following this case, this story gives us a broad perspective on the way activism and HIV/AIDS work are intricately linked. I hope this understanding will carry through into the following chapters as we read about the local prevention work youth are doing in their communities.

AIDS is transforming the globe. With the amount of AIDS related deaths worldwide escalating, there is little doubt that socially, culturally and economically we are facing a crisis. Globalization worsens this already critical situation on a number of levels. Health related issues have always affected impoverished people the most, and the strain on already poverty-stricken communities of dealing with illness increases the nature and depth of poverty. Families are pulled in many directions trying to cope with dying parents and children as well as extended family, while at the same time they are using valuable time caring for the ill in the community and in their families. Often the job of caregiver is deferred to women in the home, increasing their already heavy workload.

At the same time, the structures of globalization as defined through international agreements and governing bodies like the WTO and the IMF increase the divide between the global North and South. The TRIPS agreement has significant implications for providing adequate medical care and drugs to poor countries (and bodies). It is difficult to read the statistics of infection and not question the motives and means behind the movement of the virus. The virus reads like a stain of imperialism, moving to decimate whole populations of those who have been 'problematic' for the State: women, homosexuals, blacks, and the poor. In South Africa alone, about one-in-nine South Africans (or 5 million people) are living with HIV/AIDS (UNAIDS, 25).

South vs. North

Globalization, although not the only factor, is a key ingredient to the way in which virus has flourished in the North and South. The raging racism and colonial attitudes that marked the appearance of AIDS in North America will not be easily forgotten or reconciled and have been discussed at length by many practitioners and scholars such as Cindy Patton (1990, 1994, 19996, 19999, 200), Paula Treichler (1988, 1999, 1999a), and Simon Watney (1997). The body of the 'other' was immediately identified, classified and excluded. In North America, that body was homosexual - and if not homosexual, it was most assuredly black and from Africa or Haiti. These compartmentalisations could perhaps just be seen as a knee jerk reaction based on the fear of the HI virus itself in the general public. More likely, they were based on deep-seated prejudices and racism.

This kind of ‘othering’ allowed for a division between those at risk; ‘deviant’, ‘guilty’ and ‘dirty’, and those who were not at risk; ‘normal’, ‘innocent’, and ‘pure’. As Nicole Vitellone (2002) acknowledges, theorists such as Cindy Patton (1990,1994), Sander Gilman (1988), Evelynn Hammonds (1986), and Simon Watney (1994) amongst others, have all discussed the implication of the ‘other’ body. She writes,

Analyses of the media, especially feminist analyses of safer sex discourse, have all pointed to the way in which the constitution of health and illness – through media representations – has tended to inscribe other bodies and identities as pathological, dangerous, and diseased (Vitellone, 19).

Increasingly, as globalization re-defined the international stage for AIDS to be played out upon, the ‘other’ became the African, the Haitian, and the poverty stricken, who lived out of sight and out of mind. As Cindy Patton (1996) has written the divisions themselves were part of the large scale failure of HIV prevention initiatives – a failure we are still dealing with. The easier it is to point the finger at someone else, the easier it is to feel you are not implicated yourself. The inequalities across wealth, race and gender, have been exemplified and highlighted through the continuing process of globalization which positions one group of ‘wealthy’ people, against the ‘other’.

The process of defining this difference has become part of the process of globalization and the various agreements and international corporate and government bodies forming around it. Borders became a part of the language of AIDS and the separations imposed between us, dividing those ‘unwanted’ bodies from the rest (Ruiz, 2002), a process both in

conflict and in harmony with globalization. In conflict because global trade breaks down barriers between countries, yet in harmony because globalization creates a new set of distinctions and divisions based on wealth, access, privilege, and gender. I quote Patton (1999) at length for her astute observations of the boundaries and boundlessness of AIDS.

Internationally, AIDS is constructed through a deadly set of assumptions about cultural and political difference. AIDS is mapped directly onto pre-existing national and cultural formations. But HIV knows no geographical boundaries. HIV traces a geography unrecognized by governments' intent on reducing sexualities which subvert economic production, thwart social control, or merely stand as politically embarrassing reminders of richly symbolic and less rigidly conformist ways of life, once characteristic of traditional cultures, but now labelled as perverted and as a political liability by Western discourse. HIV follows the lines of transportation created by capital investment and traces a geography of bodily pleasures that defies the medical cops who police every country's border, no matter how many tests they devise. The HIV epidemic poses a unique moral challenge and will re-form both the meaning of sexuality and the meaning of local and international cooperation.

(Patton 1999, 400)

This kind of 'us' and 'them' discourse has become a staple of globalization, as it was during colonization. The difference posed by AIDS now is exactly as Patton has stated – the geography traced by AIDS has no boundaries. The boundaries it does have, unfortunately, trace the lines of inequalities of gender, sexuality, race and class. This can be said in relation to the view of Africans (and the very real infection rates and deaths) and it can also be seen

here in North America as well, where women, young gay men, aboriginal communities and Haitian communities continue to be hit hard with the virus. Speaking of the way in which Haitians in Haiti and North America grappled with the social accusations of their presumed 'guilt' in spreading HIV, Paul Farmer writes:

Regardless of their ultimate origins, Haitian readings of AIDS and social responses to it are redolent of their readings of the world in general – a world where power and wealth and health are so unevenly distributed. (Farmer 1992, 243)

It has become increasingly impossible to discuss AIDS without looking at the international, global structures in which it exists. The lack of equity between peoples across North and South makes a even a cursory reading of AIDS without a political analysis nearly impossible.

Trade-Related Aspects of Intellectual Property Rights (TRIPS) and Globalization

Poverty and poor health go hand in hand. In the world's least developed countries, life expectancy is a third less than in the richest ones. Many people in the South die from diseases that in the North have been mostly eradicated or are easily treated. (Forman 2002, 4)

TRIPS presents some serious and immediate consequences for the South⁵. TRIPS is an international agreement which focuses on intellectual property rights – or patents. In the context of HIV/AIDS, TRIPS has specific implications on pharmaceutical companies'

⁵ The Panos report "Patents, pills and public health: Can TRIPS deliver?" (Foreman, 2002) has been instrumental to me in writing this section.

production of drugs. As set out in TRIPS, there are a series of patent regulations that all WTO member countries must comply with under their membership obligations. Although some of the current interpretation of TRIPS is contested (see AIDS Law Project recent report, 2001), at present it prohibits countries from acquiring or producing generic anti-AIDS drugs (amongst other drugs). Many countries have been contesting, both on economic and ethical grounds, their forced compliance with this agreement as part of their WTO membership. Notably, Brazil and South Africa have maintained a strong position and have fought to provide their populations with generics, with varying success. Thailand's attempts to do the same caused the United States to impose \$165 million in trade sanctions, in response to American pharmaceutical companies' claim that they were losing \$30 million a year in sales due to inadequate patent protection. Studies such as the Panos report, *Patents, pills and public health: Can TRIPS deliver?* make strong arguments as to why TRIPS is biased towards Northern economic interests. While some efforts have been made to provide access to medicine in the South, the fact is that the majority of people in need of drugs cannot access them. In many cases, these people are poor women. While infection rates explode in the bodies of women world wide, the cost of drugs themselves continue to climb as does the separations between rich and poor.

The large pharmaceuticals attempt to make a case for themselves by stating that drug costs are only a minor variable in a whole range of factors that make treatment inaccessible to developing nations and people, such as corrupt governments and lack of health care infrastructure. Yet, even a cursory look at the profits made by the drug companies' points to a system bent of profit making before the interest of people. The pharmaceuticals are predominately Northern based, and, as Foreman points out in the Panos report:

The (pharmaceutical) industry spends more on advertising and marketing new drugs than on R&D and until very recently, pharmaceutical companies were consistently among the world's most profitable commercial enterprises...The industry has been the most profitable in the US for each of the past 10 years – in 2001 it was five and a half times more profitable than the average for Fortune 500 companies. The compensation (salary, shares, bonuses etc) paid to the industry's highest officers reflects this: in 2001 the five highest-paid drug company executives received over \$183 million, considerably more than the entire health budget of many impoverished nations (Foreman, 9).

Interestingly, even though the pharmaceutical companies argue that they have invested huge amounts of money into R&D, “seventy per cent of therapeutically important drugs introduced in the US between 1981 and 1991 were produced with government involvement; some, such as AZT, DDI and D4t, which are all used in HIV/AIDS treatment, have made considerable profit for their manufacturers”(Foreman, 9). The argument that the industry is just recovering costs put out in the research phase is really not justified – economically or morally. Prices of drugs in general are reflected by what the market is willing to bear, not by what the need may be in a developing context.

HIV/AIDS continues to threaten high-income countries, where approximately 75 000 people became infected with HIV in 2001. A total of 1.5 million people are now living with the virus in these countries, where two pronounced changes have become

apparent in recent years. About 500,000 people are receiving antiretrovirals.

(UNAIDS 2002)

Once again, we see that the interests of people living in the South are not a priority to government policy formation, multi-nationals and the process of globalization. The strong arm of the US and its economic interest, which is invested in a full adoption of TRIPS, is hard to ignore. Many observers are calling into question the legitimacy of any international agreement that puts trade before human rights and even the WTO itself has cautioned on this front.

The Canadian HIV/AIDS Legal Network in partnership with the AIDS Law Project in South Africa produced the report *TRIPS and Rights*, in which they outlined an argument about the legal obligation of states to provide adequate protection of the health of its citizens. They argue that trade and economics must not supersede human rights, and that TRIPS needs to be ratified to reflect this. They state:

...surely the need for affordable medicines in the context of widespread illness such as the HIV/AIDS pandemic is a clearcut example of a case in which States' obligations to act to protect and promote the human right to health is unquestionably of a higher legal(as well as ethical) order than the protection of private patent rights (Elliott 2001, viii).

Trade cannot, and most definitely should not, overpower human rights as are guaranteed in a full-range of international agreements that have preceded TRIPS and the current discussions on the FTAA.

Part of the bedrock of capitalism is based on the exploitation of individual inventions and patenting. It makes sense then that the TRIPS agreement is deeply embedded into the policies and agreements of this new global order that is dominated by American capitalism and imperialism. It has become clear that the way that globalization is evolving is through the expression of economics and trade. This is the very language that the various international agreements speak in, and it can veil the reality that a whole range of issues are affected through these agreements – in this case, TRIPS challenges the ability of governments to adequately provide care and medicine for their population. The language of trade has taken supremacy, at least in the WTO and in agreements such as the FTAA and TRIPS, over the language of human rights. Civil society, activists, NGOs and government bodies are increasingly challenging this dominance, largely pushed forward by the US. The AIDS pandemic has put fuel in this fire, pushing to interpret the process of globalization with immediacy.

The Treatment Action Campaign (TAC)

To illustrate how the language of rights is chipping away at this seemingly insurmountable system, I will focus on a particular successful example of the Treatment Action Campaign challenging the patents regime. I think that it is important to look more deeply into the actual situation affecting South Africans on the world stage to better

understand how youth activism and arts-lead strategies that help build on existing civil society movements can be important in tackling the pandemic. By analysing the particular case of TAC vs. the Pharmaceutical Manufacturers Association, we can dig into some of the underlying issues around AIDS in South Africa. Of course in the summer of 2003, the situation of treatment has somewhat shifted since Thabo Mbeki's government decided to give in and rollout⁶ ARVs. I will briefly discuss the situation in 2004 at the end of this chapter.

In 1998, the Pharmaceutical Manufacturers Association (PMA) took the South African government to court to contest an amendment to an Act put forward in South African parliament in order to make essential medicines more affordable. The PMA, made up of about 40 major pharmaceutical corporations, contested the Act, saying that it violated the international patent laws contained in the TRIPS agreement. In light of these disputes, the lobbying force of the pharmaceuticals led to South Africa being placed on the US Trade Representative 'watch list' by the United States. As Fred Abbot aptly points out:

The decision by the United States government to use its economic power as a weapon against developing countries fighting a battle against a deadly plague would plausibly lead developing country government officials and common citizens to question the economic, social and political foundations of the TRIPs Agreement.
(Geffen 2001, 9)

⁶ The government is using the term "rollout" for anti-retroviral drugs to mean that drugs and treatment are planned to be accessible throughout the country.

In 2001, once the case was on its way to court, TAC asked for permission to join the as *amicus curiae* (friend of the court). This request was granted and from that point on TAC used the case to bring forth various levels of civil society driven advocacy and mobilization, which eventually lead to the PMA withdrawing their case. This case, and the civil society approach to disrupting 'business as usual' practices for multi-nationals can be seen as a template for civil action and advocacy in an era of globalization.

TAC's entrance into the case

Firstly, it is necessary to define a few terms. A "friend of the court" means that TAC could submit evidence and arguments before the court. Although they were independent in this case, they were supporting the government's desire to make medicine affordable. It is important to recognize that the TAC formed a strategic alliance with the government to fight the multi-nationals. It is an interesting extension of the crisis of the Nation state to see civil society band together with the state in order to battle a third foe. This is one significant marker that this case illustrates; the role and relationship between civil society and states has significantly shifted.

Secondly, the Medicines and Related Substances Control Amendment Act (or the Medicines Act) deserves a bit of clarity. According to the TAC, the Medicines Act introduces three main provisions: "It makes provisions for parallel importation" (when a patented medicine is bought from another country from the same manufacturer, who offers it for a cheaper price there); "It establishes a pricing committee with the power to set prices of medicines" and, "it enforces generic substitution of off-patent medicines"(TAC 2001, np).

TAC joined the case for a variety of reasons. Their presence would increase the chance of the PMA losing the case; the judgement of the case could set a precedent for other countries in similar situations; joining the case provided an opportunity for public education, mobilization and advocacy on the issues; and finally, the TAC felt that it was high time that affordability of treatment for HIV/AIDS could not be overlooked any longer by either government or pharmaceutical companies.

Grounds of Contestations – The use of rights language

The way in which the TAC made its case is very interesting to an analysis of how civil society can use diverse strategies and the system of globalization itself to make significant wins for people everywhere. TAC made extensive use of the language of rights, and the international agreements set up to protect those rights to make their case. As Mark Heywood points out, “AIDS activism helped to catalyse an international activist movement that challenged the impact of international trade law on social and economic rights (such as health)” (2001, 7). TAC’s tactics included:

- The use of “public-impact” litigation – instead of “attempting to emasculate state power, [it] aimed to assist the government to defend its rights...to progressively realize rights of access to health care services”;
- The interplay of an argument about the state’s ‘rights’ to be capable of providing health care and the ‘rights’ of citizens to life and dignity;
- The argument that to make public health care more accessible you must also make private health care more affordable (the interdependence of the two systems), which was what the Act aimed to do;

- With the help of an excellent South African constitution, TAC used civil mobilization and the law concurrently to fight for treatment;
- They made the case, as other critics of the TRIPS agreement have before, that trade and property rights should not come before human rights. (TAC web)

Heywood writes, “the mobilization against the PMA and the other pharmaceutical company applicants was conscious and deliberate. Its success was not pre-ordained. It came about as a result of creative advocacy, skilful interaction with the local and international media, and research” (10). “[I]t provided proof that the world’s most powerful multi-national companies are not invincible and can be brought to account by well researched, well argued mobilizations. This lesson will undoubtedly inspire other social struggles” (19).

The win

There were a number of outcomes to the PMA dropping the case: Merck dropped prices of anti-retroviral a few days after the trial; two generic manufacturers used the case to support their application for compulsory licenses during the case; a Pfizer donation of an essential medicine finally came through to the public health sector; and, two other pharmaceutical companies stated they would reduce the price on some anti-retrovirals and nevirapine (for mother to child transmission). These outcomes were a direct “result of activist pressure” (Geffen, 17). It is hard to assess how much these tactics also helped to solidify the 2003 decision to rollout ARVs, but a strong case could be made that the continued pressure and presence of civil society activists mobilizing on these issues was a strong factor in this decision.

Implications for civil society activism

A lot has been made of TAC allegiance with the government on the PMA case, but it should not be unjustly overstated. The allegiance was strategic more than anything else, and really didn't entail a lot of interaction between TAC and the government officials. TAC's wins in this case highlight the various means and tactics that can be used effectively to bring about real change, even in the face of what seems to be insurmountable woes. This is a perfect example of post-modern politics, in which a localized struggle (in this case the struggle to provide medicines to people living with HIV/AIDS in South Africa) can have global implications (by bringing large public and international attention on trade policies which value rights to property over human rights).

The continuing imposition of trade agreements and multi-national's interests onto AIDS care, treatment and prevention has a direct impact on the bodies of real people. Many people outside of the TAC in the fields of law, health, cultural studies and social sciences are calling for a revision of the TRIPS agreements (as well as to the structure of Free Trade Areas of the Americas), which can include real commitment to upholding human rights. It is not just, they argue, that any people in the world should be denied medical care and drugs in order to protect the interests of some of the most profitable corporations in the world. The language of rights, on which most of the TAC arguments are based, can form a solid basis for resisting the continuing imposition of globalization of trade on the bodies of poor, marginalized, individuals. There is great potential for fueling well-designed civil society movements that use various tactics, from advocacy, to legal routes, to mobilization and education. The crisis of the nation state and the simultaneous strengthening of the state

through the support of (and conflict with) civil society is an important sidebar in this struggle. It is irrevocably clear that non-state players have significant powers in these matters as well. The bodies and lives of men and women in the South are depending on those in wealthier nations take up this fight with them, and not allow the process of corporate globalization to trample over their basic rights as human beings.

Update: The Rollout of ARVs

A great deal has changed since I began writing this chapter⁷. This situation has had many ups and downs along the way, but I felt it was critical to reflect at least one moment in the fight for treatment in this thesis. While things are looking brighter in South Africa at the moment in terms of treatment, it is critical that we understand the context that has caused such a difficulty for people living with HIV and AIDS to receive support and the climate of activism that exists around these issues.

In a win that happily surprised a great many activists, the South African government announced that it would begin an antiretroviral (ARV) rollout throughout South Africa in August of 2003. The intentions of the rollout, which was widely thought to be the result of both internal and external pressure on the Mbeki government, is to make ARVs accessible throughout the country to those in need.

⁷ For a more detailed analysis and discussion of the South African governments stance towards HIV/AIDS and treatment, see the excellent edited book by Kyle Kauffman and David Lindauer. 2004. *AIDS and South Africa: The Social expression of a pandemic*. New York: Palgrave MacMillan.

Finally, after a long struggle the government committed to a treatment plan on August 8, 2003, which culminated with the adoption of an action plan on November 19th. At the time of the writing of this thesis, there have still been delays in getting the rollout underway and the TAC continues to pressure the government to live up to its promises.

TAC also achieved another big win in 2003, following another litigation through the Competition Commission. Through this case there was an unprecedented settlement agreement with Boehringer Ingelheim and GlaxoSmithKline that have resulted in lower priced antiretroviral medicines for sub-Saharan Africa.

While Khayelitsha, Cape Town's biggest township and the location of much of my fieldwork, has a concentrated TAC presence, people are still struggling for treatment. At the same time, the Western Cape continues to be an example of positive change for the rest of the country. As TAC noted in their annual report for March 2003-February 2004:

Treatment is more widely available in the public sector in the Western Cape than in any other province. By the end of February 2004, slightly fewer than 2,000 people were on treatment as part of the rollout of the treatment plan. Although a considerable amount of the resources for the programme come via non-governmental organisations (NGOs), provincial government has displayed genuine political will to start the programme. The productive working relationship between the Western Cape Department of Health and the TAC has resulted in community involvement in many of the antiretroviral sites and is likely to lead to a number of joint public education initiatives...The relatively swift rollout of antiretroviral

treatment in the Western Cape presented an opportunity for the TAC to organise and celebrate the one year anniversary of rollout in Gugulethu, where 350 people were on treatment by August (TAC 2004, n.p.).

The world is watching these events with great interest. South Africa is finally in a position to change the condition of the millions living with HIV in the country, and everyone hopes they will act swiftly and efficiently. It is not yet time to celebrate, as many provinces have no concrete rollout plans in place, but change is definitely on the horizon more than it ever has been before. It is within this climate of activism and great social crisis that I turn to the prevention work undertaken with South African youth.

CHAPTER THREE

Sometimes research begins where you least expect to find it. For me, the work in South Africa on HIV/AIDS began with a fateful meeting with Dr. Claudia Mitchell at McGill University. I was busy preparing a youth photography project with a team of young women artists, researchers and activists. We met Claudia to discuss our own work and lots of sparks flew around the similarities between what we were all doing. Not long after that meeting, I started working with Dr. Mitchell at McGill. Since then, we have done a number of projects together, and the work I ended up doing in South Africa relied a large part on the work I had been doing as part of her research team in the *Soft Cover* project, which I will describe here. It was there that I first started working with the youth group that would make up my core participants over the following years. It was with this same group that I did my fieldwork (described in Chapter Four). The work I discuss in this chapter has been the result of research carried out, and writing in collaboration with Claudia Mitchell.

As we continue to work together on arts-based approaches to youth sexuality and HIV prevention our development of Geertz's (1974) notion of thick data builds. To understand the field work I did in Cape Town in the winter of 2004, it is necessary to see it through the context of the beginnings of my relationship with this group of young people in South Africa and the questions that we first started investigating in 2002.

⁸ This chapter was adapted from an article and a chapter both co-authored with Claudia Mitchell and Ann Smith. Walsh, Shannon, Claudia Mitchell, and Ann Smith. 2002. *The Soft Cover project: youth participation in HIV/AIDS interventions*. Agenda: Empowering women for gender equity. Durban: Agenda Feminist Publishing. (53)

Artful Engagement

What impact do the acts of engaging, acting, and producing have on our personal, political, and social responses? Is the very gesture of being engaged in doing in and of itself significant to shaping an individual and her/his worldview? These questions have been central to our investigation into how art and activism can be integrated into a more comprehensive strategy for HIV prevention work involving youth. Inequalities of gender, sexuality, race and class are all critical to how the virus has flourished. At the same time, while the individual is not the *only* site to navigate in creating an effective prevention strategy, it is central in the empowerment of each individual, as well as the broader social structures, to encourage safer sexual practices.

In this chapter I will explore the ways that being *artfully engaged* is contributing to the empowerment of a group of young people in South Africa to take action in relation to their own bodies, sexuality and HIV prevention. Specifically, I will discuss the work I was involved with in 2002-2003 as part of the *Soft Cover* project, a Canadian Society for International Health initiative, involving the Centre for the Book in Cape Town and a small group of youth from the Western Cape, to explore some of the issues and concerns to ensuring gender-sensitive and participatory approaches to HIV prevention with youth.

Over a period of thirteen months we worked with a group of 15 young people from several township schools near Cape Town in an arts-informed international health project called *Soft Cover*. As we describe elsewhere (Walsh, Mitchell and Smith 2002) *Soft Cover* is a youth-based participatory approach to AIDS prevention, focusing on how both male and

female youth (ages 16-19) can become involved in a hands-on visual and literary arts project that provides a youth-to-youth vehicle for addressing issues of sexuality and AIDS. In essence the project is meant to explore a youth action space approach to HIV prevention.⁹ In mapping out the project we were concerned with a variety of factors, including the particular vulnerability of youth to HIV/AIDS and the fact that the "sick of AIDS" information-overload phenomenon (Mitchell and Smith 2002) challenges us to invent new ways to get youth excited about prevention¹⁰.

We have been interested in situating two interlinking dimensions in our work. The first—the backdrop to working with youth and youth culture—relates more generally to the significance of the arts in AIDS activism. Art as activism has found a deep root in the cultural consciousness of the 21st century through the response to HIV and AIDS worldwide. Probably no area of public health has been more the subject of the arts than HIV and AIDS, ranging from the Names memorial quilt project to Mapplethorpe photography, from Femi Kuti songs to Hollywood and experimental films, to the inclusion of major art exhibitions at the large AIDS conferences such as those held in Durban, Barcelona, Montreal, and beyond.

The second is the necessity to define youth at the center of cultural production—as the producers of messages related to HIV and AIDS, and to provoke them to define their own

⁹*Soft Cover* was a partnership between McGill University and the Centre for the Book in Cape Town. It was funded through CIDA/CHIR's HIV/AIDS Small Grants fund, Phase II.

¹⁰ The idea of 'AIDS apathy' has been discussed in a number of places as an emerging reaction to prevention campaigns, over saturation of messages, and drug availability in some cases. See Schoofs M, 'Apathy, lack of funds imperil AIDS prevention', *Village Voice*, July 12, 2000

responses and needs. Our argument here is that youth culture already exists as a potentially rich artistic space for arts activism in relation to body and sexuality. Youth culture is the core of the adolescent society, and the types of images and messages that exist in that terrain will define, supplant and inform the way that their social network functions. Youth culture itself is filled with artistic representations. As any expert in product branding will tell you, tapping into the visual and stylistic meaning of *cool* is the ever-elusive prize. It is youth themselves who are actively involved in creating that meaning, so it seems self-evident that it is the youth who should be enjoined to create cool messages around HIV prevention. From glossy magazines, hip hop CD covers, black nail polish and blue hair, to graffiti, and anim , youth culture overflows with visual imagery.

Art, AIDS and Activism

A history ... remains to be written about how participation in ACT UP and AIDS activism has influenced an entire generation of cultural workers, whose work continues to blur the boundaries between art and activism, even when it is produced individually rather than collectively. (Cvetkovich 1996, 196)

Artists, who in many cases also became activists, found themselves at the centre of the first campaigns around AIDS in North America in the 1980s, with groups such as ACT UP heading the movement towards an artfully engaged activism. This arts-activist movement sparked a huge amount of cultural production, from posters and text works, to paintings, performance and video. What it also did was to create a community of people who felt implicated in the fight against AIDS, even those who were not (at that time) seen as personally at risk, such as the lesbian community. Emerging from some of the productions

made at this time were comments about the effect that this engagement had on people's lives, very literally sustaining the lives of those suffering from later stages of AIDS related illnesses (as discussed in the 1989 video *Work Your Body* by the New York City Gay Men's Health Crisis). In his 1993 video, *Fast Trip, Long Drop*, Gregg Bordowitz talks about his feeling of unity as an AIDS activist with a community that helped him to recognize, and to face, his addictions and his HIV positive status.

As I discuss in Chapter One, researchers have commented that the extent to which an individual feels vulnerable to AIDS informs his/her condom use (Patton 1996; Crimp 1988). The ways that individuals identify and relate to the world and the culture around them can greatly inform prevention strategies. While this is not to say that an individual is solely responsible for condom use, especially given our knowledge of the obstacles faced through inequalities of gender, poverty, and violence, the role the individual plays in sexual negotiation still remains significant. The view of self, politics and society has been lodged deeply into issues around AIDS activism and has helped to shape the notion of a 'cultural activism' (Crimp, 1988). As Anne Cvetkovich observes in elaborating on Douglas Crimp's earlier arguments:

'cultural activism' also makes a stronger claim about culture's role in political activism, challenging the assumption that issues of representation or discourse are secondary to the problem of finding a medical cure or changing government policies (1996, 182).

Not only does arts-informed cultural activism explicate our personal relationship with the issues, it also can have a broader role to play in our political and social environments. In this type of discourse, the relationship of the arts and popular culture to HIV prevention and AIDS awareness can be repositioned. Arts and culture inform our identity directly, so if our spaces are occupied by a culture that clearly defines our personal and social relationship to the pandemic, we are far more likely to recognize our own personal implication. In the complex discussions around how earlier HIV prevention campaigns went wrong, one point is constantly harkened back to: heterosexuals and the general health system constructed AIDS as *someone else's* problem (Patton 1996).

As I have outlined in Chapter One, Patton has elaborated this theory into one that situates the current “tropical model” concept of AIDS as a problem belonging to *someone who lives somewhere else*. (2002) This position places a great deal of emphasis on the fact that strategies did not enter the cultural or social sphere for a number of groups (i.e. heterosexuals, minorities, lesbians etc.) as a key to their failure. From this analysis, it seems apparent that any newly constructed campaigns must sit squarely in the cultural spaces that are significant for various groups of people. As Cvetkovich states:

... AIDS activism [and] sexual politics [and] sex-positive imagery that has been produced by ACT UP and other groups, far from being a pleasurable luxury, is central to the job of addressing the cultural assumptions that have resulted in an inadequate response to AIDS (1996, 183).

For youth, AIDS activism can be reflected in music, clothes, magazines, movies, music videos and the art of youth culture. Art and creativity are the hinge that unite youth to their self-definitions and social representation.

At the same time, sexuality is not only positioned through our personal and social environments. For Gary Dowsett (2000), the idea that sex and sexuality is defined by our relationship to society is simplistic. He argues that situating “bodies-in-sex” as central to the study of sexuality, informing and shaping society and culture, greatly changes and deepens our understanding of sexuality: “...bodies-in-sex are not awaiting social inscription: rather our sociality is built through the sexual, and through the enactment of desire” (41). This construction tells us that bodies-in-sex have a particular and precursory relationship to our identity construction. They are tangled into how we define ourselves and how we see society, as much as society, culture and community define how we construct our own sexualities. What he is arguing here is that these two relationships are not isolated, but have oscillating relationships that inform one another. The “sweat, bump and grind”, the making love vs. fucking, and the subtlety of eroticism, are just that much more difficult to define, quantify, and even qualify. Dowsett’s argument, we offer, broadens our understanding of ourselves as sexual beings with yet another dimension to consider as we struggle to create effective HIV prevention strategies. Sexuality, then, can be positioned somewhere between the personal, the socio-political, and the body itself. This reading of sexuality demands a complex approach that takes into account the varying intersecting identities of any one individual.

Globalized Messages

Work in South African schools around gender-based violence also uncovered the problems with using one globalized message in HIV prevention strategies (Mlamleli et al 2001). Again we find that messages must be contextualized and positioned in the communities they are made for. An acknowledgement of Catherine Campbell's (2002) notions of social identity and social capital (see Chapter One) are useful here in considering the way messages and educational work is targeted at specific communities. Mlamleli et al's (2001) work challenged educators working with youth to investigate globalized HIV prevention strategies, such as— **Abstain; Be Faithful; Condomise** – which leave little space for considering the vulnerable position of many young women. Participants were encouraged to think up alternative ways of naming these ABCs, such as **Aggressive masculinity; Biological vulnerability; Coercive sex**. In that work, the team of researchers and educators were drawing attention to the fact that the ABC strategy ignores the significance of gender to HIV prevention strategies and its generalized and simplistic message in the end discourages youth from creatively exploring ways of encompassing healthy sexuality and desire within a safe-sex lifestyle. In our work in *Soft Cover*, we found that the young participants agreed with this analysis. As one young male participant noted during the workshops:

I could say that the ABCs - Abstain, Be Faithful, and Condomise, they are missing something 'cause sex is a natural thing...I think they should change that strategy. Condomise should stay, but the A, B - Abstain, Be Faithful...it can't be like that...it won't change.

Youth as Cultural Producers



Figure 1: MSE making Heal mural

Central to this project is the idea that youth need to define for themselves the prevention messages that pertain to their own bodies. One way to facilitate this was to bring youth together to work with a cross-section of writers, artists, graffiti writers, musicians, activists, filmmakers, and entertainers. One example could be seen in the short film *The Moment* directed by South African filmmaker Siyabonga Makhatini that looks at “the moment just before penetration and the question is whether to have safe sex.” Humorously, but also poignantly, the viewers are all left with the question: At which moment do we decide to use a condom? A second way to facilitate youth participation in the issues is to engage youth in producing their own art and creating their own cultural spaces.

Within the discussion of prioritizing youth voices lies a key concern — how do we avoid romanticising the voices of youth, and how do we ensure that the presence of young people is much more than a token gesture towards inclusivity?

We attempted to address these concerns in the symposium by ensuring that the young people who attended the symposium were given space to prepare to participate actively and energetically in the proceedings; they were not merely voices who had been recorded by fieldworkers or teachers, nor were they just there to prove the inclusivity of our project.

Their voices as experts on their own lives as youth were given as much, if not more, weight than those of the other (older) participants. We also built in follow-up workshops that I will discuss below.

Workshops and Book-Making

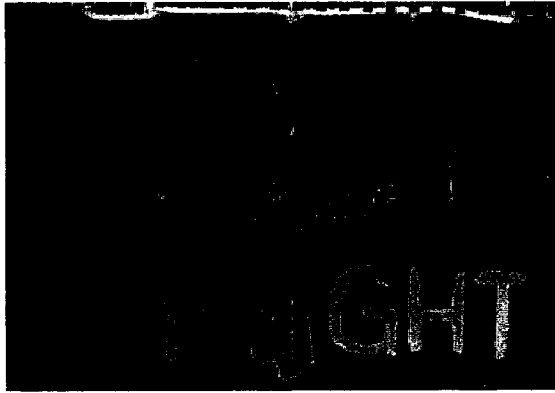


Figure 2: Book Cover

The same fifteen young people who participated in the symposium came together over seven sessions to participate in a practical hands-on implementation of some of the ideas that surfaced during the symposium. In this phase, the focus was on practical workshops where the participants had a chance to learn more about how to go from the readings, discussion and information around HIV and AIDS to visual images, poetry and narrative. The overall process was highly participatory with youth identifying and following up the issues that they thought central. The challenge of the workshop was to create a book (text or image based) that addressed some of the topics that emerged in the symposium. Over the course of the seven sessions, local illustrators, visual artists, poets, hand-made bookmakers, and authors directed the book making workshops. HIV/AIDS activists and community workers also came in to work with the participants about prevention language and strategies that could be reflected in their writing and visual images. The sessions also dealt with issues around gender, HIV/AIDS health and prevention issues, sexuality, message making, creative approaches and the social/political context of AIDS amongst other topics.

For example, two HIV+ women came in from the Memory Box project to teach book making to the participants. Memory Box is a project in which people living with HIV and AIDS create a box full of artworks, stories and memorabilia from their lives. Abigail Dreyer, a gender facilitator from the School of Public Health, University of Western Cape, also did an intensive session around gender and violence. The book-making component of the project culminated in a book launch at the Centre for the Book in which friends, community members, teachers, principals, parents and other youth attended. Several months later the youth also presented their work in their schools with public readings that drew on the individual action plans of the youth participants.

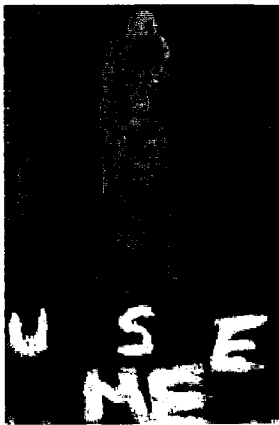


Figure 3: Visual image from *Soft Cover workshops*

One of the boys, Tumi, was interested in talking about HIV and AIDS in the first person to personify the condom and the virus. In one of his poems *Acquired*, he writes, “the sunshine has gone/the storm is here/...I must show apartheid that I am not like him/ No one will ever beat me/...ambulances up and down/because of me/hospitals full/ because of me/...ashes to ashes and dust to dust/ for what? /because of me/HIV.”

In one of his visual pieces, he applies the same personification approach to the condom (see Figure 3), playing on the double meaning of both a condom asserting itself “use me!” and the sexual connotation of submission. He used various shades of purple paints and glue to give a very tactile feel to the image.

His identification with AIDS and apartheid was not isolated. We were taken with the way that he shaped AIDS into a human form, an enemy to fight. We also saw in his writing his own sense of the impending doom of the situation. It is evident from this approach to writing that young people are aware of the illness and death related to AIDS all around them. The sense, again, of struggle politics and activism was also very present in the way this young man saw HIV/AIDS.

In My Life: Youth Authors

A number of months later, based on the enthusiastic response of the young people to the writing they did in the bookmaking phase of *Soft Cover*, we convened a series of workshops on writing about HIV/AIDS in your life, facilitated by Ann Schuster, a renowned South African writing teacher. The workshops and book that emerged from them was called *In My Life*, and took place at the Centre for the Book in Cape Town and culminated in the publication of an anthology of youth writing.

“This is a true story and I am the narrator of this story,” writes Lindeka Cynthia Rwidia, one of the young authors in the anthology, *In My Life: Youth Stories and Poems about HIV/AIDS*, as a closing line in her piece, *When AIDS came knocking at my door*. Many of the participants were from the original *Soft Cover* project, but a number of new youth participants were involved as well from communities nearby.

Clinton Stempel



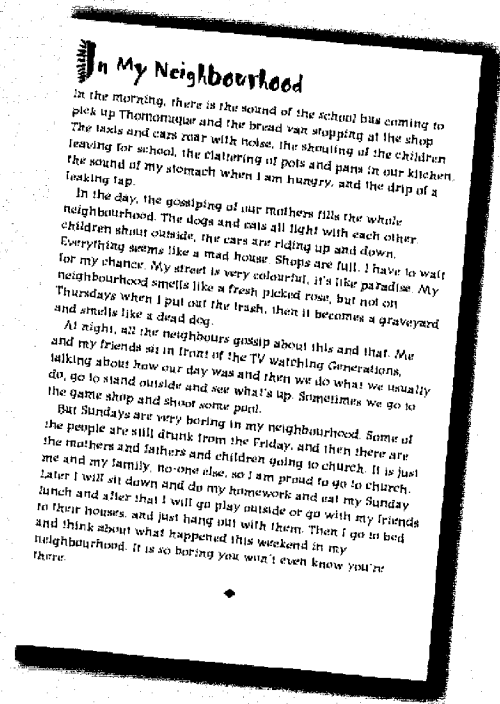
I am Clinton,
who remembers his first day at school,
and loves school now,
who remembers the day his grandmother died
and who knows that she is now in peace,
with God,
who dreams of becoming a doctor,
who dreams of romantic things,
and whose dreams will come true
one day.

I am Clinton,
a 15 year old boy
who loves to go out and
meet new people and have fun,
who is talented and smart,
almost perfect!
I love tranquility, opera, music
R&B Bass

I am Clinton
who lives in Cofda,
a small village in Retreat.
And who was born on a Sunday,
on the 13th December 1987.

I am Clinton
a dancer at the Junior Resource Centre
in Retreat
who hates people with a bad attitude,
who doesn't eat chicken skin
who sometimes feels afraid when he is alone
but not as if in the dark or being bullied
but in his heart
because people can hurt a person
very deeply
and think nothing about it

50 IN MY LIFE



Youth stories and poems about HIV and AIDS 51

Figure 4: Example from *In My Life*

In my Life investigates how HIV/AIDS plays out in the lives of the youth participants, in their homes and their communities. It is striking in the finished work to see the enthusiasm and the dedication of the youth to come up with new and inventive ways to tackle the AIDS pandemic and to keep getting the word out in their communities, schools and peer groups.

The writing within the anthology, which I do not have the space to discuss in detail here, has had enormous impact so far in South Africa and is in its third reprint. The enthusiastic response to the collection of writing by educators, young people, HIV/AIDS organizations, and NGOs has again reinforced for us the need for youth authored and produced materials to take center stage in creating viable and engaged prevention strategies.

Unravelling the Data

Holland et al (1999) use the term “unravelling” to describe the process of working with the variability in young women’s accounts of negotiating and decision-making in talking about condom use in the UK. What strikes us in our unravelling is that it has been the deep

structure — the “thick and deep” — of the responses of the 15 young people collected over a period of time and through an ethnographic arts-informed approach that has provided insights into the complexity of issues related to negotiating sex, condom use and so on, as opposed to the automatic answers that we were hearing in other data gathering situations with youth: "Wear a condom"; "It is the equal responsibility of the boy and the girl"; "You have to have respect"; "You have to protect yourself"; "You should be in love", and so on. These are young people who are very knowledgeable on how they *should* respond and so digging out deeper meaning to what they were saying often proved difficult.

By using the structure provided through the engagement of artists and writers as facilitators and involving the youth themselves in making art and doing writing, the surface structure of their answers began to peel away. A key feature of this unravelling and peeling away comes from working with poetic and visual images. As Gabriele Griffin observes:

Images...are subject to conventions, conventions of what a society encourages to be seen and what it suppresses from sight on the one hand, and conventions governing different kinds of representations on the other. (Griffin 2000, 178)

An engagement with youth in defining and defying these conventions, so laden with contradictions and tensions, has the use of writing and images as central tools. Unearthing the deeper meanings through complex forms of getting at and ‘reading in’ to the life stories of the young participants is also necessarily tempered by their engagement and willingness to tell their stories. Indeed, the space that the arts and culture played in the wider structure of

the life stories of many of the 15 young people in the group became increasingly apparent through our sessions.

Reference to *The Moment*, for example, kept popping up in the conversations the youth were having both formally and informally during the workshops and discussion periods. While they would often only make brief reference to the video, they used it as a means to start to talk about their own feelings around the delicate issues of sexuality and AIDS. The video seemed to have opened up a common space between the participants in the group and a common experience through its content.

Karyn: I always think of [*The Moment*]. I think to myself, Ok, then when is the right moment to ask to use a condom? Cause, I mean, it is really complicated, so you really do have to sit down and talk about it first.

The conflicting emotions between wanting to use a condom and being unsure how to negotiate its use could be vocalized through the provocative and safe space created by the video.

Consider too Karyn's comments as she discusses with the group how she was confused by actors on soap operas and in the movies who never used condoms. Her cultural and social world included these fictitious spaces as signifiers for her own behaviour. For her, recognizing that those spaces were not "safe" was frustrating.

Karyn: I'm gonna go back to the movies... I mean, [the movies] present sex as though there is no risk involved, I mean, no pregnancy, there's no AIDS, there's no STDs; it's just free and out there, you know, and anybody can have it anytime with anybody!! You won't get anything; you don't have to worry about it. There should be, maybe there is on some teen movies—a girl who falls pregnant—but then there are her friends who are even bigger 'sluts' [she makes the "" gesture with her fingers] than she is, and it doesn't happen to them. But everybody is at risk of getting pregnant – except for the guys [laughs] – and contracting AIDS and STDs and they must highlight that in the movies...

She clearly articulates her concerns about risk here, and links these concerns specifically with the culture of image and video around her.

Thabo confirms the idea that popular culture might distort what counts as risk when he makes a “pretty girls are safe” comment: “We say that a beautiful woman can't have HIV. That is something risky; since she is beautiful she can't have HIV.” He goes on, however, in the same interview to point out that the term risk for him and for his male friends may have other meanings. As he observes: “Last year they told us that girls should put the condoms on their boyfriends, and one of the guys did do this. He said ‘My girl, come here and put on this condom,’ and the girl came to do that, but that guy — I think the penis was that long [indicates about 60 cm with his hands], and the girl said ‘I am going to pee and I'll be right back’, and the girl never returned.” The risk is that there may be no sex at all!

On the one hand one might be tempted to put the comments of Karyn and Thabo into the category of myths about AIDS, fitting right in to “you can cure AIDS if you have sex with a virgin.” In the case of Thabo's comment about the large penis, we might even see him as being somewhat facetious, or playing to the group, making the comment as part of a discussion group where his friends were also present. But for us, the idea here is that the social is not the only component that contributes to the larger framework of sexual reality, juxtaposed by the joking way Thabo discusses "bodies-in-sex". As Dowsett claims,

just as there is no longer room for a biology, a physical science of the body, separate from the social body, so a social theory of the body that neglects its biology remains flawed. The body itself teaches and inscribes (2000, 37).

While it is beyond the scope of this chapter to provide in depth case studies of Thandi, Thabo and Karyn, like Holland et al (1992), we argue for a more situated understanding of the varying terms and expressions youth may use, and consider that we need to make space for the personal as part of a local context, in the same way that we also need to make space for the local as part of a global context.

For example, sex for many young women in South Africa is not consensual even if the young woman does not overtly resist (Mlamleli et al 2001; Human Rights Watch 2001). As Thabo points out “disappearing to go pee” may be the only way out. Thandi, a young woman from Khayelisha highlights the danger when she talks about being involved with a violent gang from the Cape Flats. She stumbles over her words to try to explain the complexity of the situation:

Those guys they make their own ... (pause) their own kind of like ... go and steal this ... or force their girls, and say let's go ... they don't want to give their girls a choice to say ... when they decide it is time to have sex, the girls always say 'yes, yes, yes' because the girls are afraid of them — because they beat them all the time. ... Like girls, when you say to the boys, let's just break up, he will say you can't do that to him, and he will beat her. The girls are afraid because you don't have power to beat him.

When we locate her answers within a life history approach there is more to them, and to her hesitancy to answer. It may not just be because she is in a larger group or that the group is a mixed group of males and females — both possibilities that would allow us to interpret her behaviour a particular way. Is there trickiness in the questions that we raise that have held her back? How does transactional sex enter into the biographies of participants? Thandi is poor and bright and she needs to finish school. She lives with four brothers and may understand a great deal more about male sexuality because of this. Are our questions — or the space within which to answer them— too small? How can we widen the space, allowing for her to find the ways in which she needs to express herself, her desires, and her concerns? These expressions are not only for research, or researchers, but for Thandi as an individual and for her relationship to her own peer group. I will come back to Thandi when I discuss how girls in our group are representing themselves and their concerns around HIV/AIDS in their lives.

The strategy of *working with* rather than *working for* young people has the added advantage of ensuring that both the medium and the message are localized and personalized. One of the limitations of many HIV/AIDS campaigns is the idea of one-size fits all. This ignores, in particular, the gendered face of HIV/AIDS, and the differing social contexts for young women and young men. Young women in South Africa need to produce and consume knowledge and skills-building information that equips them to navigate a risky landscape — where being able to see themselves as ‘knowers’ is key. They need to know how to survive, as well as to negotiate the power relationships in their sexual encounters. Young men, on the other hand, need to produce and consume knowledge and skills-building information that offers alternatives to a dominant discourse that equates aggressive masculinity with being seen as a ‘knower’. By working with (rather than for) young people directly and in localized settings, there is greater possibility of ensuring the centrality of the personal in beliefs, attitudes, behaviour and activism itself.

Potential for Engagement

AIDS is a nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another.

(Treichler 1988)

Art is not only useful for creating and opening spaces for youth engagement with the difficult issues of sexuality and AIDS, but has the potential for politically activating youth.

As Aggleton and Warwick argue,

the key to effective work with young people, . . . lies in establishing a productive level of complementarity and commensurability between interventions of different kinds, not in searching for one particular solution that ‘works’. (1997, 88)

From this perspective, the inclusion of youth within the process of developing prevention strategies and ideologies is key, combined with the idea that there needs to be a diversity of strategies that respond to the varying needs and responses of any one community of people. The overlapping nexus that Treichler speaks about, and the various approaches Aggleton and Warwick have alluded to, must not go unheeded. We need to create various methods and means of engagement that not only provide an opportunity for us to go thick and deep in our understanding of the issues as researchers, but also that create an activated space for youth.

What being artfully engaged within the *Soft Cover* project has demonstrated to us is the significance of developing frameworks that blur the boundaries between research and action and that place at the center the possibility that the participants themselves see ways of taking action in their own lives. For example, Claudia Mitchell reports the following from her field notes:

When I visit Thandi’s school several months after the launch of the book of poetry that she has written, Thandi speaks before a school assembly of 1700 students about her involvement in the project and of the importance of taking HIV prevention work seriously. She confidently reads several poems that she has written as part of the project. The thunderous applause from the audience is only one aspect of her

activism. She is also now involved in a journalism project on Saturdays and she has decided that she wants to be a writer when she finishes school. While we are not sure what action the principal and teachers in the school will take, we can see by their expressions at the assembly and afterward that they are impressed by Thandi's dedication. In a follow-up English class that we participate in, some of her classmates want to know if they too can write poetry about AIDS and whether it can be published.

While there are no surefire solutions to combating what is clearly a crisis situation amongst young people in South Africa, and while we need to avoid romanticizing the long-term impact of moments like these, we nonetheless are optimistic that it is moments like these that are a necessary precondition to young people taking action. From the work in *Soft Cover* it has become apparent that youth have been provoked to question themselves, to discuss among their peers and to feel personally implicated by AIDS issues through the arts. This, coupled with the positioning of youth as active agents in producing messages and assuming a voice in the discussion around HIV/AIDS strategies, can potentially charge current strategies: *the personal is political* is turned on its head to read as *personal engagement creates political action*.

It is the idea of young people as both producers as well as consumers of knowledge (Buckingham and Sefton-Green, 1994) that we think can help young people to become 'knowers' in relation to HIV prevention. This point of view has resonance with the ideas of engaged pedagogy and critical consciousness that I outlined in Chapter One (hooks 2002; Campbell 2003; Giroux 1991, 1996, 1997). It is therefore essential that programmers ensure

that young people themselves are actively involved in both creating and critiquing the texts around them. This approach, at least in theory, appears to be gaining wider acceptance, as indicated by Peter Piot at the Fourteenth World Congress on AIDS, Barcelona, 2002 session *Youth speaking out*: “We are working with young people instead of working for young people.”

From this perspective, then, it also became important to uncover how further sustainable links could be made for the youth involved in this project to continue spreading the message and owning the process. Chapter Four will look more depth about what the youth in this project were able to do when they set their own limits and created their own projects from start to finish.

CHAPTER FOUR

When I use ‘passion of experience,’ it encompasses many feelings but particularly suffering, for there is a particular knowledge that comes from suffering. It is a way of knowing that is often expressed through the body, what it knows, what has been deeply inscribed on it through experience.

(hooks 1994, 91)

In this chapter I would like to discuss the research I conducted in 2004. This aspect of my fieldwork was also the last official project of the group that had been working together under the *Soft Cover* rubric over the last two years. In this the final phase of the project, the work took on a slightly different tone. This was partially because most of the young participants were entering a new phase of their lives. Most of them were finished or finishing Matric. A few were starting college or university. In general, these were no longer high-school going young people. Their relationship to the work we had done and the work they would do around HIV/AIDS in the future had shifted. For some, it seemed that the project would fit into *cool things they did while teenagers*, for others, the work had taken on quite significant proportions (paired with other HIV/AIDS work or experiences they had had) and they were ready to continue with the project.

When returning to South Africa, one of the first things I did was reconvene the original group of young people who had been involved in the *Soft Cover* project. We had always been

working with youth who were based in different communities around Cape Town, and by this point, getting them to all come into town was a tall order based on a number of factors, the main one economic. So rather than meet as a whole group, we started working together in two separate groups, one based in a sandy isolated town called Atlantis, about 60 km up the coast from Cape Town, and the other group based in Khayelitsha, the largest black township in the Western Cape, about a half and hour's drive from the city.

The entire original group who had continued working with the project lived in one of these two locations. I made the drive out to Atlantis and Khayelitsha to have group meetings and discussions. My coming and going in itself slightly shifted the way the project had been operating. Earlier, working with a local organization, the Centre for the Book, had meant meeting in the Central Business District of Cape Town. This neutral zone had been convenient in some ways, but meant that for every gathering, transportation for the young people had to be factored in and figured out. While making the *Fire & Hope* documentary¹¹ I had the chance to visit everyone in their homes and do one-on-one interviews, which added a layer to our notion of thick and deep description. It also made me more aware of some of the contradictions with their *theories-in-use* and *espoused theories* as I gained deeper access to their lives. For me to go out 'there' I quickly realized meant something different for the group, and for me. In both locations, a white woman, even a foreign white woman, coming into the community on a regular basis was remarkable. Locality, context, personal issues were suddenly struck in relief. In Khayelitsha, for example, Xhosa became much more commonly used in our group discussions. Where I couldn't understand, I would get brief

¹¹ *Fire & Hope* is a documentary I directed with the young people in the *Soft Cover* project about youth activism and AIDS in 2003. See Appendix A.

translations at opportune moments, or at the end of the session. In their own environments their participation seemed more comfortable and in control.

The issue of language itself revealed aspects of my interactions with the group that had been hidden to me before. Thandi had always seemed shy and withdrawn to me. While this continued to be true of her, I realized that her Xhonian identity was quite a different thing. She was more animated and outspoken, even in groups dominated by male voices. Her character grew and changed in complexity.

As this phase of the project got underway, it was clear that the Core Youth Group consisting of the original members of *Soft Cover* would now often be working in two separate spatial entities—the Atlantis Group, and the FA.T.T. working group in Khayelitsha, mainly due to localities and language. I will explain here the work that happened in Atlantis and in Chapter Six I will go into some further detail about the Khayelitsha FA.T.T. video project in Chapter Six that deals more specifically with film.

Workshops and Research

A. Core Youth Group

The core group met over fifteen sessions. In this group we focused on getting deeper into the ways that peer education has worked for them thus far and developing an action plan to spread the message in the youth networks that already existed for the core group. We also discussed obstacles they are having still around sexuality and AIDS issues, and how to integrate what they have learned through the project back into the communities in which they live.

This process was very intense and rewarding. It was through these discussion sessions that we worked out and fine-tuned the work they wanted to do in this final phase of the project. During this process, I kept field notes, gave guidance and support where necessary, and sometimes recorded the session for transcription. All the projects listed in the following few pages were the result of the core group working sessions and the decisions we made therein.

B. Atlantis—Young people illustrate the impact of HIV/AIDS on their lives

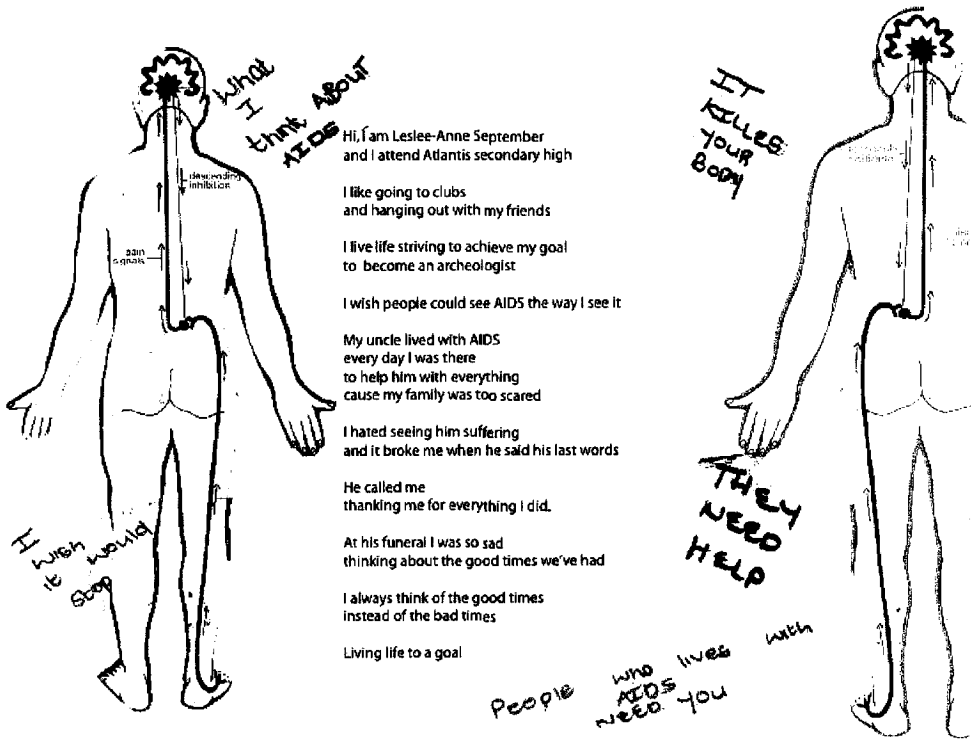


Figure 5: Page from *Voices from Atlantis*

The work with youth in Atlantis uncovered many of issues that were critical to young people around HIV/AIDS and sexuality. The integration of writing, drawing and discussion group sessions allowed for some of the contradictions between *theories-in-use* and *espoused theories* to be highlighted. While I do not have the space in this chapter to address all of what was discussed and uncovered during the Atlantis fieldwork, I would like to spend some time unpacking the collaborative process undertaken by the group and a few of the key findings that are relevant to a discussion of sexuality and AIDS with young people.

It has become clear through this project that a pointed investigation of violence and gangsterism must be factored into any program on sexuality targeted at young people in contexts such as Atlantis. What does it mean to construct a healthy sexuality and to protect yourself from HIV infection, illness and death when you are an ongoing witness, perpetrator or victim of violent crime? While attention has been paid to how gender-based violence increases HIV vulnerability, I would argue from the work conducted in Atlantis that a deeper investigation into how poverty and gang-related activity impedes and constructs hegemonic masculinities and risky environments for young people must be undertaken. We must also ask how girls construct healthy and productive notions of desire and body image in a context where there is such a high level of rape and acceptance of sexual harassment. The challenge for educators, and in turn for engaged researchers, is to understand the emerging conflicts and contradictions inherent in a context where coming of age sexually also includes a stark awareness of violence, illness and death.

In this chapter I will focus on the working sessions in Atlantis, including how the core youth group became involved in their high school as facilitators and AIDS activists. I will

also highlight my own interpretations of some of the data they uncovered through their writing, drawing and discussion sessions with the Student Representative Council.

Led by the Core Youth Group, we conducted an intensive three-day workshop on HIV prevention at Atlantis Secondary School in Atlantis, South Africa. There were 13 youth involved between the ages of 14 and 17. Four of the Core Youth Group members led the sessions with my help. Sessions were designed around the work done in the *Soft Cover* project and included a full-day writing session on issues of HIV/AIDS in the learner's lives, a painting and drawing workshop based on the writing and prevention messages, as well as a full day learning and discussion session. I draw on my field notes to explain the beginning of this process:

Today was the first session with the Atlantis kids and it went marvelously! I feel so excited and rejuvenated about the project all over again. I went house to house and met up with Morgan, Karyn, Shamema and Abigail. The principal ... has been really pleased with the project so far and we talked about the fact that the kids we've been working with were moving on to university or jobs. He expressed some concern about how to continue the AIDS education with other learners in his school. ... Once we all got together... everyone expressed interest in continuing working as a team and doing something with the learners in the school as well. Things quickly started to take form. We watched the video again (*Fire & Hope*) and they began brainstorming about what they would like to do in the high school. I was really amazed. I was no longer guiding the process almost at all. They discussed the various approaches they could take in the arts and writing – what kind of learners

they would want to have involved (Karyn even had some learners in mind) and how to focus the teaching. ... They also began discussing age groups and how learners even as young as standard 5 (11 years old) were having sex and needed to have access to this information. In the end, they decided to involve older serious learners in a small group format to get into issues more deeply with the aim of developing some kind of outreach tool (writing, an exhibit, a performance) that could reach younger kids as well. We decided on a meeting date for next week.

When I left, I felt elated. They are as dedicated as ever and have really taken the work on in their own hands... We have become like a group of peers, which is so interesting, and my role has almost erased itself that is wonderful. I'm excited to see what we will end up doing! (January 2004)

The planning and implementation of the work with the Atlantis group, as I indicated in my field notes, was very smooth and directed by the youth themselves, with ample monitoring from the High School principal. They finally decided on running three days of workshops with the Student Representative council. After each session, we would regroup, discuss the day's events and plan for the future. Often we met in a little Kentucky Fried Chicken—one of the few restaurants in Atlantis—that sat on an empty field surrounded on all sides by the ghetto-style projects. I was continually impressed with the way the Atlantis group was willing to take on a great amount of the responsibility and make the workshops really work in a way that made sense to them.

The Core group in Atlantis and I began the discussion session with the Student Representative Council (SRC) group in earnest under a big tree in the field of the high school—which was the only spot we could get in the overcrowded school. Karyn did introductions of the group of peer facilitators and what they had been involved doing in our *Soft Cover* project. About half of the learners did their introductions in Afrikaans, as it was a mixed group of Afrikaans and English students. Their ages ranged from 14 to 17. Only one boy in the group had obtained any kind of formal AIDS education before.

There were lots of questions about the myths and stereotypes around HIV/AIDS, and the other youth facilitators did well answering all the questions they could. We used handouts and fact sheets on HIV/AIDS and gender issues associated with AIDS. The group talked a lot and brought some very earnest questions to the discussion. One boy piped in and asked, “What are the symptoms for people with AIDS? What does it look like?” Karyn explained in Afrikaans that you could not always see AIDS on someone. He continued his questioning, “Why would one person who infects another live longer? Why would the person who had become infected die first?” A girl asked, “How do you get it? Can it come through skin?” The group was quite concerned that you could get AIDS from kissing or from skin to skin contact with someone with AIDS. They started talking a lot about this. One boy said that people with AIDS should drain their blood so they couldn’t give it to anyone else. There was obvious concern in the room about the routes of transmission. While in general the young people were fairly knowledgeable about HIV and AIDS, there were some moments where the embedded discrimination and stigma attached to the disease (such as the examples cited above) were evident. I was concerned about the multiple and

persistent questions about the routes of transmission, but we felt that it was good that we were undertaking the education session.

Violence and Desire

As the discussion group and workshops continued it became clear that many of the girls seemed afraid to have *any* sex at all and were quite nervous about AIDS. For girls, there seemed to be something just below the surface of the discussion that indicated they felt unsure about any kind of complete safety. Looking at the statistics of sexual violence and rape in their community made it quite evident why they may feel that way. On the second day of our workshop sessions, one of the youth facilitators spoke directly to the issue.

Abigail: I'm still a virgin, but that's mostly because I'm so afraid of getting AIDS. I guess that I'm abstinent by choice, but, it's more like, I just don't feel like I would be safe with a condom. I don't know....

After Abigail's comments I wondered about the way we are constructing healthy sexuality as educators. While of course we need to drive home the potential danger of unsafe sex in such a high-risk environment and break the myth of any *absolute safety*, scaring young people completely out of their own sexuality cannot be desirable either. The comments of these older, activist girls were important to reflect upon. This is compounded by the high rates of rape and sexual violence in Atlantis, and South Africa more generally, where girls are already living with a sexuality associated with fear and violence. It still remains a question for me how to educate on safe sex and AIDS while retaining a focus on a positive emerging sexuality.

At the same time as girls were expressing their apprehension about *any* safety, a few boys in the discussion groups unequivocally stated that that girls who go to places where there is drug and alcohol use or even to a boy's house almost deserve to be raped. While the outspoken males in the group might have wanted to rile up the group by this provocative statement, other boys in the room nodded in agreement. And, while some of the girls (mainly the older ones) were loudly opposing this idea and there was also some general laughing and joking about it, there were also three or four girls in the room who appeared to feel uncomfortable as to whether or not there was some truth to this claim. The confusion went so far as to have some of the girls contesting what kind of situations girls would be unsafe in. As I saw later in the writing group, girls in Atlantis often have direct experience with sexual violence in their own lives and the males seem quite insensitive to the situation and don't always see sexual violence as a problem.

A few young women agreed that it was not fair to make girls feel that they can't go out and have fun like everyone else.

Norman: Well, why would girls go to places like that where they know it is dangerous?

This comment left a dead silence in the room. It seemed that no one was sure how to answer this question. Finally one of the female facilitators piped in.

Karyn: Because they want to have fun!

The discussion was heated and showed the tensions within this group about what was appropriate for girls to do. The girls themselves were judgmental of 'girls who did that' and were obviously trying to figure out for themselves what they should or should not be doing.

The ambiguity around how these young people saw girls' vulnerability resurfaced again a little later in the discussion. Earnestly, one of the more religious boys in the group asked,

Norman: Why do girls go out with gangsters who beat them?

Leslie-Ann: Maybe you lost your virginity to him...

Abigail: The violence starts slowly and only gets bad once you have been with him for awhile. By that time it's too late...

The girls seemed to have lots of answers as to why they would be dating gangsters, of which there are a lot in Atlantis. It appeared from the tone and quality of the discussion that both girls and boys in the group thought it was average or normal to be in a violent relationship. Suddenly one of the cocky and outspoken males loudly spoke up,

Lorenzo: Some girls need (to be hit) these days.

This time, his comment wound up the group, many of whom made it clear that they did not think that this was an appropriate thing to say, either by loudly opposing him or rolling

their eyes and using other body language. At the same time, the fact that this comment was made at all was telling of the level of violence in the community.

Again, as I indicate in Chapter Five, the contradictions between sexual desire, sexual activity and rape were continually issues that arose in group discussions. Hegemonic masculinities were very prominent in the mixed discussions, with the older boys usually leading. While the boys often led discussion, there were also a few interesting moments when boys showed their vulnerability and uncertainties around sex. One younger boy, Romeo, said that the problem for guys is that they don't know when they are making out when it is the right time to bring out the condom. "It seems to the girl like I'm trying to pressure her," he said, "if I bring out a condom."

This was a different take on how the 'moment' could be difficult from a male point of view. I also took note of how this boy, unlike in the discussions that I discuss above, was concerned about even *appearing* to pressure a girl to have sex. It was interesting to see how the group had a sense of what they should answer ("guys should always introduce the condom"), but on interrogation, changed and elaborated their positions. Often we have focused in the literature on how women have difficulty negotiating condom use, but Romeo brought up an interesting and little discussed aspect of male difficulty in condom use.

The 'moment' is a resurfacing theme that I also discussed in Chapter Three and it should be a place on which to focus further educational work. What actually happens right before sex takes place? How do you introduce a condom? Are there other safe sexual activities you might want to keep in mind in the case there is not a condom available?

Romeo's candidness was also illuminating in terms of the difficulties for males to show uncertainty and vulnerability around sexuality. It is critical to allow spaces for boys to investigate their own vulnerabilities and fears in sexual relationships.

Overall, the group was quite open and inquisitive. Unfortunately the older boys often dominated the conversation, but there was sufficient back and forth to get commentary from almost all of the young people. Interestingly, while we know from statistics that girls in this community are often having sex at younger ages than their male counterparts, it was the older boys in the group who talked in more experienced ways about sexual matters. Again it seemed a case of girls protecting their reputations and boys not feeling the need to do so.

The questions and comments that arose in the group discussions often seemed to come from personal experiences, but the dialogue continued on an impersonal level. Having Karyn and the other older students run the workshop had an evident impact on the other learners. These youth leaders were respected in the school and the younger learners had an easy time chatting with them—apparently pleased that they could hang around with the 'cool' kids. There was overall quite a lot of conversation about different aspects of AIDS and they asked a lot questions. By the end of the session, one of the male students made a point to say,

Norman: We need more AIDS workshops run by the kids we know. The other students in this school would listen to us way before they would listen to adults and

teachers. Using music, art and writing makes it more interesting and you actually want to learn.

The Writing Session

The following week we met together to do writing and drawing. When asked to write on the topic *In My Neighbourhood*, 11 of the 13 group members wrote about witnessing extreme violence or a killing. This finding is also important to assess in terms of the impact of AIDS on the lives of youth in respect to their ability to make positive life choices. If young people are living in environments of extreme violence, where life is seen as insignificant, the ability and desire to protect themselves from AIDS may well seem of minor importance.

The thing I fear most in Atlantis is

The high crime

The gang related wars

Atlantis has a lot of talent

All that we need is a good system and

More people to look up to in our community

People who can show our children

There are much greater things in life to do than

Increase our crime rate.

(Quinton, *Voices from Atlantis*)

Sex itself may be used as an escape from violent surroundings and of course, and most significantly, the amount of sexual violence is heightened in an environment such as this. In the writing session on *When I feel scared* many of the girls in the group again alluded to their ongoing fear of rape, which surfaced more when we talked about the poems after the readings.

When I am scared...

I feel like I am going to die

Old memories from my past come back

I feel like the ground can just give in underneath me

I feel like I can disappear into thin air

(Kashiefa, *Voices from Atlantis*)

Many of the young people talked about how they had rarely been able to tell their stories before. This seemed to be a significant space to share with each other stories that emerge from the particular context and place they live in.

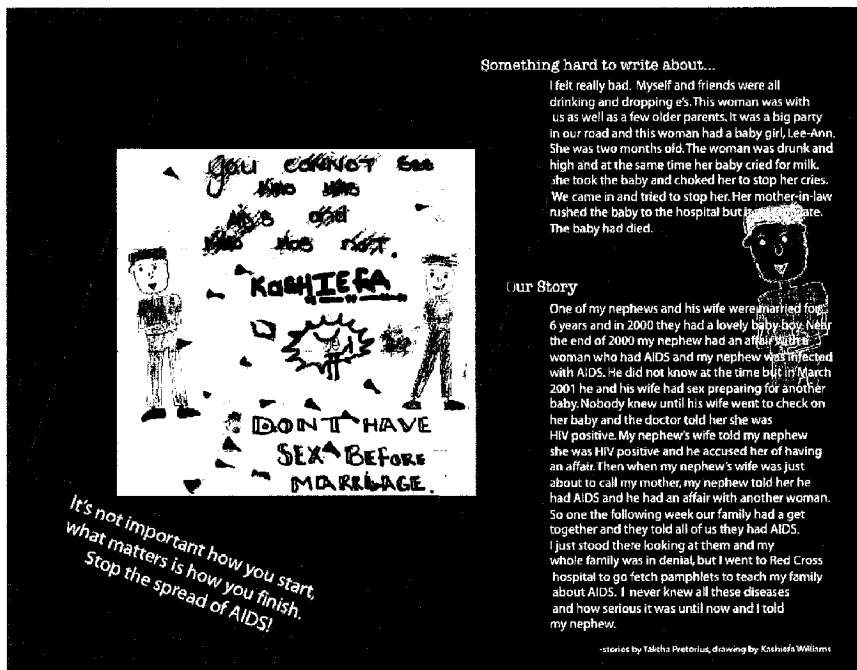


Figure 6: Page two from *Voices from Atlantis* (Appendix B)

Voices from Atlantis

After the workshops were completed we put together the drawings and writings in the form of a spiral bound book titled *Voices from Atlantis* (see Appendix B). There were copies made for the school, the Core Atlantis group facilitators, for me, and for CBIE/CIDA (who funded my research). There were also laminated copies of each individual page made for the authors themselves.

As I mentioned above, the topic *In My Neighbourhood* elicited some very vivid responses from the young authors. The following poem stuck with me long after the book was finished. For the young man that wrote this poem, it is evident that the violence and tension in his community are a source of great pain for him. This, ironically, was the boy in the group who made the comment that “some girls need to be hit.”

In some neighbourhoods
not much strange things happen
but on one specific day
something you have nightmares about happens
and you are involved
and almost pay with your life.
You ask yourself 'where is the love?'
and some people just tell you
shut up
shut up
shut up

(Creswell, *Voices from Atlantis*)

The final refrain “shut up, shut up, shut up” echoes and reflects the feeling of many of the youth I have worked with in South Africa. It reinforces the sense that young people’s voices and needs remain unheard.

The process, though by no means an extensive analysis into the lives of youth in Atlantis and the ways AIDS affects them, has been an entry point for Atlantis Secondary School in tackling these issues in some new and innovative ways with young people leading the process. Luckily, the social capital at play in this particular context allowed for some sustainable work to be undertaken.

The following are two short pieces on AIDS that came out of the writing workshop with the SRC.

I remember my friend's uncle just becoming sick, and really sick. It seemed like he was one step closer to dying. He went to the hospital and they told him he had AIDS. I didn't actually know what it really was at that time, but the more I went with my friend, the more I found out. At first I felt disgusted at the way he looked. He was only a skeleton with skin, coughing after every single word he said. I did a bit of research and books told me that nobody actually knows how AIDS started. I thought then 'How am I supposed to know and to learn?' till people came to our primary school and told us how it can be prevented. The only thing they said was abstinence. The older I got the more I started hearing of condoms and so forth. AIDS has become so important to me that right now I'm in an AIDS workshop learning to teach others the facts.

(Lorenzo, *Voices from Atlantis*)

In this selection, Lorenzo has been affected himself but he is also inspired to continue learning and talking about the issues. This boy was one of the most enthusiastic about continuing to spread the message to his peers in his school. Like Lorenzo, many of the young people in Atlantis had personal stories to share about the way HIV/AIDS had affected their lives, even though they often felt before the workshops that they did not. One of the strengths in the project was the way it brought forth the various stories in the group.

In Romeo's piece, he talks about the common feeling amongst youth that AIDS is a 'boring' topic. Overcoming this 'boredom barrier' must also be central to any successful prevention project targeted at youth.

I can't remember the first time I heard about HIV AIDS. I've heard so much about it that it actually became a boring topic. When people say they are going to an AIDS conference I would say 'no thanks, I'm not interested in going because I don't think they'll say something I haven't heard before'. When you guys came along, I started seeing the AIDS topic from a new point of view. I actually enjoy AIDS discussions for the first time in my life. Thank you for making me see that it isn't all that boring to talk about AIDS.

(Romeo, *Voices from Atlantis*)

Romeo was resistant to the project at first. In fact, in the first discussion group I commented in my field notes that this boy wanted to challenge everything being said about AIDS. It was interesting to see him come around and start to share some of his own personal stories as well.

The Core Group has established an action plan for the remainder of this year to continue following the progress of the SRC, giving support where necessary. They also have planned to run the same workshop for the SRC at the beginning of the next school year. The principal of Atlantis S.S. is very involved in the project and will be working with the Core Group on monitoring the progress of the SRC as well as ensuring that the group has access to school space and resources where necessary.

Violence and gender inequality are still major issues for young people in protecting themselves from infection. Inequalities (social, economic, physical) are preoccupations of many of the young people in these groups when they discuss making positive change. Atlantis in particular has so much gang violence that many of the discussions about our lives ended up exploring the extremely violent world these young people are up against.

CHAPTER FIVE

This is a true story and

I am the narrator of my story.

(Lindeka, *In My Life*)

Taking a gender and action-informed approach in South African led me to look more closely at the texts and transcripts done with the young women in our groups. As discussed in Chapter Two, gender dynamics and power relations are a critical element of HIV/AIDS work. It seemed crucial to reflect on the 'thick and deep' of girl's stories and experiences around HIV/AIDS. As time passed during the project, the contradictions and variations in the girls' stories engaged and intrigued me. It also pointed me towards a more situated understanding of what young women in very particular contexts were dealing with, in this case the contexts of Atlantis and Khayelitsha, South Africa.

As Mitchell and I (2004) have argued elsewhere there is now a plethora of programs and campaigns that purport to address the issues—ranging from addressing safe sex, voluntary counseling and testing, stigma, transactional sex and gender based violence. Yet for a variety of reasons many of these programs appear not to be working. We have found in our own work and in reviewing other studies that young people are saturated with too many messages, as well as messages that are often based on fear tactics. Youth are suffering from

¹² This chapter is adapted from a paper co-authored with Claudia Mitchell that was first presented at the Annual Conference of the American Educational Research Association (AERA) in San Diego, California, April 2004.

information overload which has resulted in “AIDS apathy and fatigue” (Mitchell and Smith 2001; Mitchell and Smith 2003; Schoofs 2000). In terms of content, popular ABC HIV prevention campaigns in South Africa leave little space for considering the ways gender operates in sexual encounters. As Mlamelli et al (2001) addressed in their guide to working with educators on gender-based violence issues, the ABC message ignore the significance of gender to HIV prevention strategies and its generalized and simplistic approach seems to have discouraged youth from creatively exploring challenging ways of encompassing healthy sexuality and desire within a safe-sex lifestyle (2001). These kinds of programs really seem like they ignore the everyday realities of young women.

As Wood, Maforha and Jewkes (1998) write:

Comprehensive and innovative intervention programmes need to be informed by localized research into: how constructions of gendered difference are formed, operationalised and enacted; the range of motivation for adolescent sexual experience; how adolescents negotiate and resist sexual access to their bodies...the different social contexts in which adolescents act; and the social spaces where communication about sexuality is practiced.

(Wood et al 1998; 240)

It is critical to take into account the details about young people’s lived experience and how it relates to HIV and AIDS. While it is understandable that there is a real imperative to find a universal HIV prevention message that young people can relate to, it is also imperative that

we do not lose sight of the fact that for many young people a generalized message may go entirely unheeded.

From the work we have been doing in South Africa there appears to be a real need for multiple programs and projects that take into consideration the details of young women's (and young men's) lived experience. The research in South Africa has been an entry point towards operationalising a longer-term 'research as social change' project. With the idea of digging deeper into the meanings and the situated-ness of young people's stories, I would like to turn our attention to the stories of two of the young women we have been working with over the last two years.

In this chapter I focus on aspects of the 'life-stories' of 2 young women—Thandi and Karyn—with whom we worked over a period of close to 2 years as part of the *Soft Cover* project and this research project, *The Ground Beneath Me*. The term 'life stories' is used here in a tentative way because they in no way reflect the whole story, and, as Mitchell and I have discussed elsewhere (2004) and I further elaborate here, the stories change – both because time goes on and new events have happened in the lives of Thandi and Karyn over the two years we have known them, but also because even the events of the recent past become open to new interpretations as time goes on and we look back over the transcripts and our field notes and understand the girls (aged 16 through 18) better from a deeper overall conception of their lived experience.

I am interested in this chapter in looking at some of the gender dynamics that arose in the group I was working with and the ways in which gender issues play a significant role in

the young women's self-construction. What does it mean, for example, to participate in HIV prevention programs while being confronted with violent sexual relationships? What does it mean for girls to deeply understand their vulnerability and risk to HIV and still feel incapable to change their experience? How do we as researchers deal with the fear that girls are living with and how do we create programs that do not make girls completely repelled by their own bodies and sexuality itself?

Finally, how do we work with data across the personal and the collective? This is something that Catherine Campbell (2002) has highlighted when trying to understand why AIDS programming in South Africa does not seem to be significantly impeding the epidemic. As she, writes:

the social construction of gender serves as a key obstacle to condom use. Sexual behaviour change is more likely to come about as the result of the collective renegotiation of young people's gender and sexual identities than through individual decisions to change one's behaviour... a key precondition for behaviour change is the development of a critical consciousness of the impact of gender relations on sexual health. (133)

Thandi and Karin: Statistics say I'm the most vulnerable

A. Thandi

Thandi, who has been mentioned above is a sixteen-year-old black girl from Khayelitsha participated in all of the activities of the *Soft Cover* project, from beginning to end. Based on her comments and her demeanor, and the fact that other kids in the group had mentioned

that she lived in off-limits gang zone, I started to think that maybe part of her withdrawn behaviour stemmed from living with a lot of fear. Her comments, when she made them, tended to back this up. Some of the guys in the group were trying to persuade the girls that in a violent situation the woman should just hit the man over the head with anything close by, such as a pot or an iron. Thandi was anxious to add to this discussion:

Like girls, when you say to the boys, let's just break up, he will say you can't do that to him, and will beat her. The girls are afraid because you don't have power to beat him. It's like that...

When I look back over the transcripts, she most wanted to speak—to share her opinion with the group—when the topic was around violence. I've begun to realize that this is more often than not the case for many young women in South Africa. Violence is inescapable, untangle-able from their ability to do or be what they want. Thandi's was the story that we hear about in the statistics. She was surrounded by friends with HIV, or those that had died of AIDS and she was also caught in a vicious cycle of violence that offered no easy escape. Negotiating safe sex, in this context, seemed like a fairy tale.

Those guys they make their own ... [pause] their own kind of like ... go and steal this ... or force their girls, and say let's go ... they don't want to give their girls a choice to say ... when they decide it is time to have sex, the girls always say 'yes, yes yes' because the girls are afraid of them – because they beat them all the time.

“The girls are afraid of them” —this line is hard to shake. To appease the situation, the girls say yes to whatever it is, including unsafe sex.

Clearly, as researchers we have to ask if we are starting in the right place, in light of Thandi’s comments, with HIV prevention? Or are we wasting our time unless we address the real levels of violence, and sexual violence, that young people are living with in their daily lives. Does prevention for girls become something that they know the right answers to, but have no means to apply? Interestingly when given a chance to write her stories as we proceeded with the *In My Life* workshops, Thandi became much more vocal. The quiet time with a paper and pen allowed her some space that the group discussions perhaps could not. She deepens our understanding of her own environment through telling the stories of other girls close to her. In one of her stories, Thandi tells us about her friend who is HIV positive. After the girl loses her mother to AIDS she finds a note telling her she too is HIV positive. Thandi’s friend sets out to find her father. Thandi tells the girl’s story:

She found him staying with his girlfriend, then the girlfriend left and my friend and her father were staying in a place which had only one room. At first my friend slept down on the floor.

One day her father said, ‘My angel, it’s cold, come up and sleep in the bed, and I will sleep down on the floor.’ After a while, her father couldn’t take it down on the floor, it was very cold, so he decided to go up to the bed and sleep next to his child. Then he started to touch his child and she was crying, saying, ‘What are you doing?’ and he said, ‘I want to do it, and don’t speak loudly because you will wake the neighbours, and if you do, I will kick you out of my house.’ The girl was

afraid to be kicked out because she had no one but her father. Then she found out she was pregnant.

(In My Life, 4)

Thandi's assessment that the girl was afraid to be kicked out echoes her earlier line "the girls are afraid of them." It is an echo that we cannot forget. The story Thandi writes ends with the friend discovering she was pregnant. What happens next? Thandi doesn't tell us. We can imagine many scenarios; the transmission of HIV to her child; her father kicking her out once he saw she was pregnant, beating her, disowning her; her own increasing sickness and poverty; or maybe there is a positive outcome – intervention, the girl connected with support for herself; her child born without HIV through early treatment. We don't know the end to the story, yet these beginnings are the key as we try to navigate the lived experience of girls and try to imagine what prevention messages and techniques will actually touch their lives.

On a brighter note, Thandi's involvement in AIDS activism and in HIV prevention projects has given her a great deal of confidence and a certain amount of status in her community. As time passed and she gained more experience speaking publicly at events, reading the stories she had written, and telling about her own life, she changed. No longer the silent girl in the back of the room, she often led the discussion and contributed her own points. As I wrote in Chapter Three, in Xhosa she is often outspoken and taking more leadership positions. A few months ago she was invited to sit on a panel with distinguished women, including Winnie Mandela. Whether this newly gained confidence equips her with the tools to deal with the gangs in her neighbourhood is hard to say.

It is very difficult to attempt to untangle the level of vulnerability that Thandi lives with. After all our work was finished with the FA.T.T. project, we got together again to do an evaluation of what had happened over the course of these few years of working together. Thandi talked about her increased confidence and changed attitude. She also told us that when men in her community find out she is a published author through the *In My Life* booklet, some stop her in the street, others ask her to marry her. She talks about how this has made things tricky for her, even though the status of being an author has allowed her privileges she would have never have had before. Even the telling of her story itself becomes a factor increasing her vulnerability, but of course, so does her silence.

B. Karyn

Karyn, a 16-year-old “coloured” girl from Atlantis about an hour away from Khayeltisha, also knows that women in her community are making sacrifices that may well hamper their ability to negotiate safe sex. Karyn has also been involved with the *Soft Cover* project since it began. The violence in Atlantis is also gendered, and girls learn this at an early age. As Karyn observes in one of the interviews:

Some women are emotionally incapable of handling [fighting]. Maybe there is a baby in the house and the woman doesn't want to scare the kids. She'll feel guilty. She will feel, 'ok, I owe him that. I owe him sex. I have to do it, I have no other choice. I can't stand up to him, he is the father of my children and he provides for my household...so I must give him sex'. That's her mindset. But I mean, emotionally she'll think this is wrong 'I don't want to do this – why do I have to

do this?’ but there’s nothing she can do about it because she gets beaten up and then she’ll go and fetch her family, then it’s a whole ordeal, and then he’ll go and fetch his family, and then it’s a family clash. So a lady always thinks of those things. Leave the peace, rather just do what he wants her to. [Other girls from Atlantis nod in agreement]

Karyn also knows what it means to feel afraid, and feel trapped. She even goes so far as to justify a woman’s reasoning to “keep the peace.” While this story is of “some woman” it is hard not to hear Karyn’s own understanding of keeping the peace and appeasing a man’s needs rather than suffering the greater consequences to family, community and self.

Throughout our meetings with Karyn, she has been self-assertive and unafraid to speak her mind. For example, she asserts that women should refuse sex to men who won’t use condoms. At the same time, contradictions abound. At one point, some weeks after she has made it clear that it is “everyone’s responsibility to insist on condoms”, she tells the group that she is unsure about when it is the right moment to discuss condom use. Her comments are interesting because she alternatively asserts, probes, and stumbles over her emerging ideas about desire, sexuality, femininity and safe sex practices. In the segment of the transcript that follows, Karyn expresses some of her opinions and thoughts about the female condom. Her first, and most resounding concern, is that the female condom would be painful. She immediately comments that “women have to go through a lot of pain” in order to use the female condom. Karyn is also concerned with the safety of the female condom. She informs the group, rather bluntly, that the female condom “doesn’t protect you from STDs and AIDS... Whereas the male condom will.”

I actually learned that on this camp that I went to and they had this AIDS workshop and they showed us the female condom and all that, and she told us that it only protects from pregnancy, so what is the use of that, so the male might as well carry the condom, OK its not 100%, but it is better than unprotected sex....

And the female condom you have to put in a few hours before you have sex...whereas with a male condom you can just be like, ok, put on the condom....A condom shouldn't be a hassle, but if you are getting a male condom it is less a hassle....

She locates this knowledge in an educational context. It is interesting that she sees the inadequacy of the female condom to prevent HIV infection as an indication that males should carry the condom. She merges the sets of information about the female condom she has learned at the camp and the media. What she says she learned from the media is even more damaging than the 'educator' at the camp:

The reason why I think that the female condom does not protect from AIDS is...there is this new one I have seen. And I saw it recently in the news...The female condom....They were talking about it on the news...and it had hooks

Another girl in the group asks, shocked, “It had hooks!...Ow!” In a move perhaps to keep the floor and the interest she was inspiring in the group through this new information, Karyn asks the group (to uproarious laughter) “Exactly where do you hook it!”

Interviewer: Do you think you would rather use female condoms or male condoms?

Three girls, including Karyn shout, “Male!” without a moment’s reflection. When asked if they would use the female condom if it was comfortable, Karyn scrunches up her face in disgust, “Putting it on totally grosses me out.”

A year and a half later, we are interviewing Karyn again, this time with the idea of making the *Fire & Hope* film.

The interview is intimate, there’s a person operating the camera, one of her best (guy) friends and me, the interviewer. We are in her bedroom surrounded by pinup pictures of the latest rock and hip-hop stars. Her room is small and overflowing with pictures of her friends, momentos, stuffed toys – she has collaged photos on the walls, a crucifix hanging on her mirror beside a beaded AIDS ribbon. Out her window is a back alley where gangsters gather at night, get drunk, curse, sing, carry on and even sometimes shoot their guns. She points out over the bars on her window onto the dusty sunlit street at the spot they’ll be when night falls. We settle into the interview. Karyn is forthright as ever and starts talking about the gangsterism in Atlantis and a girl who was recently molested right beside her house. As she speaks, though, there are pauses which catch my attention:

Shannon: Do girls talk a lot about how to protect themselves and their group of friends?

Karyn: Of course, we are nervous about it... gangsterism in Atlantis is everywhere. ... Choose your friends carefully. It's difficult to trust people unfortunately.

S: How come?

K: [silently shakes her head]

S: Ok, we'll skip it.

Karyn has always been very upfront and articulate, but her experience here is an uncomfortable one. It is not only about other people, suddenly, here in her room, with an interviewer she trusts and her best friend close by. She tells me that most girls will “be with any guy at any time.” I ask her why she thinks that girls do that:

K: Mainly because they just wanna be loved. Especially in Atlantis. Most of girls come out of broken homes, so they have no mothers, no fathers, or their parents are alcoholic, so they think this guy is wonderful and all they want is to be accepted and loved.

S: If you could talk to those girls, what would you tell them?

K: Ok, I'm gonna be a little personal, here. I'll... If I should talk to them, I'll tell my experience. I live in Atlantis and I was raped, it was very traumatic experience for me. I'm still going through it, stuff like that, I wanna educate them about it, and tell them not to trust anybody. Not to be so impulsive. Because the reason why it happens to people, or why it happened to me was because the people you think are your friends are not your friends... It just doesn't work that way. So just be careful and watch out.

As we see in this transcript excerpt it has been hard for Karyn to not blame herself (or what she sees as her own her poor judgments) for the rape. As I noted earlier, for her and other girls around her, their fear has gotten so deep about pregnancy, rape and AIDS that they abstain from sex. Maybe this is what 'grown-ups' want, but it makes one wonder, how does a girl grow into a woman when she associates her emerging sexuality with violence, death and fear? Will that attitude ever really pass away? Are we hoping to scare young people totally out of sexuality all together?

Textual Transgressions

It is critical that we not take these excerpts to be the end-all of what these girls' lived experience tells us. In fact, perhaps this research project is best at describing what we don't know—the spaces in which the girls still struggle to define meaning for themselves and places we, as researchers, can continue to find ways to access. Through these texts we can examine the contradictions and details in the narratives, which may give us some insight into the actual human idiosyncrasies that make easy answers often allusive.

As the long history of feminist interviewing demands, we must also take into consideration the fact these excerpts mainly occurred in a context where a young white foreign woman was doing the interviewing. Questions of power must also inform the way we read these interviews and may of course provide another level of entry into the way we make meaning out of what we are reading.

Perhaps Karyn and Thandi's accounts are most valuable for sending us back to the process of close readings, and for realizing that what they might have said at one point in the study is in direct contradiction for what they might have said later – even though both are true. Somehow, fastening on the truths in motion that Karyn and Thandi provide us with may be a way to find the spaces to insert HIV prevention messages that will stick.

There is an emerging body of work on engaging in close readings of transcripts that we regard as particularly useful here for acknowledging the limitations on a single reading of any one transcript. Joseph Tobin (2000), for example, proposes that like the richly textured lines

of a Shakespeare play, the transcripts of young people talking about media hold a great deal of meaning, and he argues for what he describes as ‘reading in’. Tobin looks at brief excerpts from transcripts of young people to provide a textual reading based on looking for things that don’t fit.

I’d like to draw into my analysis of the texts Lynn Mikel Brown and Carol Gilligan’s (1994) voice-centered approach to understanding interviews. For them, making meaning is about understanding relationships, and in order to do that they outline a four part process: listening to the tape the first time for the story that the person is telling, then listening the second time for the self— “the voice of the ‘I’ speaking in this relationship”. When they listen the third and fourth times, they focus in particular on how people talk about relationships:

... how they experience themselves in the relational landscape of human life. In working with girls and women, we are particularly attentive to their struggles for relationships that are authentic or resonant, that is, relationship in which they can freely express themselves or speak their feelings and thoughts and be heard.

(Brown and Gilligan 1994, 29)

Mitchell (2003) has been exploring ideas of ‘unravelling’ and ‘reading in’ the transcripts and accounts given by young people throughout the work in South Africa. She borrows from Holland et al’s (1999) use of the term unravelling, in which they describe the process of working with the variability in young women’s accounts of negotiating and decision-making in talking about condom use in the UK. Exploring the notion of feminist methodology they

talk both about the difficulty of relying solely on the personal accounts of respondents as a tool of interpretation, but at the same time, the need to start with the everyday. Speaking, in particular, about the difficulty of exploring the centrality of gendered power relations with young women as a feature of their own lives when they are not aware of gender as a construct, they observe:

... women's personal experiences are not a sufficient means to explain social practices and processes ... there is a complex process of negotiation between data and analysis. Personal experience can be valid as a source of knowledge, but circumscribed by the limits of personal ideas and practices.

(Holland et al 1999, 466)

A good example of the tensions here is the space between how Karyn makes it quite clear that women must assert themselves yet at the same time she partially blames herself for the rape when she discusses how she should not have trusted people. In the first instance her words are clearly the kind of words that would inspire others to try to be strong. Meanwhile at the level of the private and personal her experiences are quite different.

As we read in we can also look back at what has been said over time and in so doing, become more aware of the situations in which the interviews take place. Often the girls have been in a larger group of both males and females, where there is a certain jockeying to get the floor and keep the floor. Most importantly, we are aware of the fact that this text is not an indicator of knowing Thandi or Karyn – rather it is a slice of time – a brief narrative – of the interactions and narratives they weave through the conversations they are having at *this*

moment, in this space. Like Tobin (2000), our goal here is not so much to provide an in-depth case study of Karyn or Thandi, but rather to read the ambiguous statements that they make “as expressions of the tensions and contradictions” around body and sexuality more generally. When we read Karyn’s text within the context of the group dynamics and relationships, she seems confident, quick to respond, sure of herself. When we read it again listening now to the meaning she constructs over the course of the interview, we hear her fears, her worries, and her excitement and embarrassment about her emerging sexual identity. We also hear her concerns over her own femininity, and her unrelenting fear and insecurity of her sexual self in the world.

Conclusions

Like Holland et al (1999), we argue for a more situated understanding of the way young women are constructing and describing their own experiences when we look at the transcripts of Thandi and Karyn. We need to make space for the personal, as part of a local context, in the same way that we need to make space for the local and national as part of a global context of gender and HIV risks. Each of the young women in our study group is dealing with particular and situated risks. Bringing a situated understanding of where the girls are coming from together with close and detailed readings of transcripts and creative processes may well lead us towards viable ways to address prevention, risk and sexuality with young people. When Karyn tells me she had been raped before the project started, our play back of her transcript makes us wonder what meanings we should make now, after the fact, of her comments about risk and negotiation. In the case of another young woman whose story Mitchell and I didn’t take up in this Chapter, we learn some months after the initial

discussion that took place about female condoms that she has tested HIV positive. The meaning we have made of her comments before we knew this fact must perhaps be re-conceptualized and re-situated in light of these new understandings. Where her comments made from an underlying fear of testing positive? Was her occasional silence due to a mounting knowledge about her status? And when she invited all her friends and family to see her speak at our book launch, was there something behind the force in her delivery that was created through the personal journey she was undergoing?

A key finding from this work so far is that we need to be committed to resisting a quick-fix approach and instead make more visible the kinds of tensions that young people are dealing with. An additional aspect of the work with these youth has been to develop discussion guides to go along with *In My Life* and *Fire & Hope* with the idea that the kinds of accounts that Karyn and Thandi offer in these two texts can provide entry points for discussion for other young people on the day-to-day realities of their lives. It seems critical that there be space in these guides, and in our discussion and educational work with young people, that the variability and contradictions in their own accounts have space and acknowledgement. Sexuality, being at least in part socially constructed is always in flux. Our understanding as researchers of adolescent sexuality as well as educators must also be prepared to shift, embrace change and to conceptualize ways of understanding contradiction. Creating prevention campaigns with space for these things seems an absolute necessity.

These texts also indicate how the way prevention messages are often targeted and taught do not fit into the lived experience of girls. We need to better understand the issues that girls are actually facing if we intend to create viable 'gendered' approaches to HIV

prevention. If we do not listen to and deal with the realities that the girls are telling us about, there is no way we can conceptualize educational formats that will be effective in a context where girls are confronting self-esteem issues, rape and sexual violence, gangsterism, transactional sexual practices, body issues, unsupportive school and home environments, increased responsibility for sick family and friends, etc, etc.

At the same time, we must be wary of how interview data is used and the interview itself can be constructed in such a way that will reinforce the very social inequalities we are attempting to address. (See Gubrium & Holstein's edited work, *Postmodern Interviewing*, 2003) How for example would other young women respond to seeing a text such as Karyn's which we quote a second time,

I'm gonna be a little personal, here. I'll... If I should talk to them, I'll tell my experience. I live in Atlantis and I was raped, it was very traumatic experience for me. I'm still going through it, stuff like it, I wanna educate them about it, and tell them not to be trust anybody. Not to be so impulsive. Because the reason why it happens to people, or why it happened to me was because the people you think are your friends are not your friends... It just doesn't work that way. So just be careful and watch out.

Karyn's advice here might be taken as encouragement to 'say no', to fight back and to become a youth educator. Yet her own fears about being impulsive and about the reason rape happens explore some of the deeper tensions she feels about her own situation. Her story provides a real entry point into talking about young women's experience of rape and

sexual violence with other young women. Karyn's story is messy, it contradicts itself, but it also brings hope and a real-life voice that young people can identify with.

While these snatches of life histories don't give us immediate solutions and full comprehension into the issues young women face, they do begin to give us an idea about how to integrate young people into the research process – the telling, listening and recording of stories – and how that process itself can be liberating and educational.

CHAPTER Six

It has been suggested that photographic and video images can act as a force that has a transformative potential for modern thought, culture and society, self-identity and memory and social science itself.

Therefore by paying attention to images in ethnographic research and representation it is possible that new ways of understanding individuals, cultures and research materials may emerge. (Pink 2001, 13)

In this chapter I am interested in three interlinking concepts around the use of film and video in relation to AIDS: as ethnographic research tool; as a creative aspect of social intervention/activism; and, as a vehicle for narrative and personal accounts of HIV/AIDS. I will look at how the group of youth in South Africa with which I did my fieldwork used video as part of a effort to educate themselves and the subjects in their film and briefly look at how I used an ethnographic approach to *Fire & Hope* as a means to collect data in a reflexive way.

How does the camera itself becomes an element of research practice? Filming people alters our relationship with them and the relationship they have with their own identities. Filming has an implication on what kind of data we get, how that data is received, and our relationship to it as researchers. Using the examples of *Fire & Hope* (2003) and the *FACING The Truth* videos (2004) (see Appendix A) I am interested in exploring the way that film subjects have a reflexive perspective on their own lives when interviewed in front of a

camera and the ways this level of research can be used to elaborate on and extend more traditional interview transcript material. What are the research implications of changing and fluid viewpoints of our interview subjects? What is it about documentary that allows individuals to gain new perspective on their lives? How can we tap into that response in a positive way that will lead us to deeper and richer data? How does this approach fit into the larger project of *Arts-informed social change/research* I have discussed in Chapter one?

FACING The Truth: Researching with and about research

Using film as an ethnographic tool as we did in *Fire & Hope* yielded a certain type of interview data, one tempered of course by the way in which the young people saw themselves when the camera was pointed in their direction. Norman Denzin (2003) has explored some of the level of identity creation that people go through in an era where cinema and television increasingly provide us with reflections in which we locate our own identities.

He comments that, “members of the postmodern society know themselves through the reflected images and narratives of cinema and television” (142).

As Denzin has pointed out, more and more cinema and television shape the way we see ourselves and those around us. When we use video as a part of a research methodology, we must also consider how the tool itself (the camera) shapes the kind of data we obtain. For the young people I will discuss here who were part of this project, they became both subjects of the lens and producers and creators of their own images. These two complimentary and conflicting projects yielded information about both the way young people in South Africa

deal with AIDS in their lives and how that information is tempered by their particular relationship to filming/being filmed.

The world of private troubles, the site of the authentic, or real, self, has become a public commodity. (Denzin 2003, 144)

Denzin acknowledges the way that our public spaces are dominated by ideas about what the 'real' self is all about. From talk shows to news shows, interviews are used to present the 'real' truth. This is as much the case in South Africa as it is in North America. As many theorists have argued, the interview itself is something that is now part of popular culture. The way we define ourselves in an interview structure, especially a filmed interview, is shaped by this culture (Gubrium and Holstein 2003; Denzin 2003; Briggs 2003).

For this project, the data I gained from the one-on-one interviews done with the young people in their homes, yards and bedrooms was both personal and constructed. Divulging intimate details seemed to become more important when the camera lens was focused on them. As the filmmaker, I was drawn deeper into their lives than I had been over the few years of knowing them and doing group work with them. At the same time, some of the interviewees gave more pat answers than they would in the group discussion – perhaps trying to seem articulate or smart. What became clear was that the subjects were building their filmic identities in one way or another. Earlier in the discussion phase of the project, some of the young people had discussed how film and television impacted the way they thought about AIDS (see my discussion of this in Chapter three). The culture of media

around them had obviously impacted the way they thought about some of the issues and the way they would represent themselves in that forum.

I also wish to draw on Sarah Pink's discussion of ethnographic video from her book *Doing Visual Ethnography* (2001). Pink argues that traditional hierarchies between visual and textual data are not relevant to a reflexive approach to research that acknowledges the details, subjectivities, power-dynamics and politics at play in any ethnographic project. Pink, along with others (Prosser, 2001; Lomax and Casey, 1998), argues that video ethnography can deepen our understandings of our research and provide another level of entry into understanding: our own position as researchers, the subject's position, and the complex layers of intersections that occur between representation, reality, culture and meaning. As sociologists Lomax and Casey insist, "far from being a distraction or unimportant, a reflexive analysis of the research process can contribute to an understanding of the phenomenon under investigation" (1998, 6).

When the time came for the Khayelitsha group to make their own film, different aspects of their relationship to AIDS came forward. Their anxieties about race and politics became very clear as they constructed the questions they would ask, the way they would visually construct interview sites, choose interviewers and coordinators. This level of engagement—which also employed the creative process but this time in a more empowering way—led to new insights in terms of the group's feelings and insecurities about AIDS. Many of these insights were gained through an understanding of the FATT group both as subjects of my research and researchers in their own right using video ethnography in a context they were both familiar and estranged from.

First, I will look at the process of putting together the youth-authored project *FACING the Truth* and analyze elements of that project more deeply.

With a local facilitator in Khayelitsha and the members of the core group who live in Khayelitsha (and through a local computer training centre - Khay-Net) we continued with our Action Plan sessions. It was decided that this group of youth would put in a proposal they would develop together for a final HIV prevention project. They had a week and a half to put a proposal together and submit it to Mandla Oliphant, my co-facilitator, and I. These youth, who live in a black township community, had decided that they wanted to confront some of the invisible social and political realities around HIV/AIDS in young people's lives. They proposed to do a creative project around this topic and continued to lead the discussion session in terms of establishing how, where, and what they would do. Finally, through consensus with the group, they decided they wanted to make a short video. They were especially interested in showing the white faces of AIDS that are not seen in their community. Their idea was to shift the power from the standard white researcher/worker in black communities to black community members exploring, facilitating and researching with white youth.

The process of coming to terms with how this project would go was similar in many ways to what happened in Atlantis. In Khayelitsha, the group was more conceptual and broad. They were also coming from different schools (and some were even finished school) and were less situated to do a longer-term type of intervention. Mandla and I encouraged them to think of something they wanted to do that would be possible and would also launch

more education work for them in the future. Linking this group up with organizations that were interested in doing similar work became a central imperative of the process. Finally, because it was their voices that I was interested in accessing, I felt that their leadership in the process was one of the most important elements to try and maintain. Language was often an issue, but we got off to a fairly organized and comprehensible beginning with this group being very keen on making a project work. From my field notes:

I decided to arrive later than everyone else, as they seemed better off to run the meeting without my (English) intervention during this important brainstorming phase. We were meeting in a little side-room, empty but for chairs, beside Khaynet internet café which is run by my co-facilitator, Mandla. The day was hot and big patches of sun stretched across the carpets. I had left them last week with a sheet of questions to have answered for how we would proceed after this meeting. I brought pizza, but the group was so deep in discussion, even though I'm sure they hadn't eaten all day, that they just couldn't stop for a minute to eat until finally I urged them to take a break. KK was running the group more or less, as usual, but I was interested to see how Nosubobiso and Lindeka were also really voicing their opinions a great deal. Lindeka, in fact, is almost pushing the group in terms of organization, while KK still tends to wax metaphorically or to bring in conceptual ideas more than practical 'let's do it' stuff. When they had eaten and settled a little, KK presented to me what they had come up with so far. Again I was feeling disappointed that they had to switch the dominant working language from Xhosa to English on my behalf, but they seemed to not be too bothered about it. (January, 2004)

They told me that they had decided to focus on making a documentary which would uncover the 'truth' about AIDS and young people by interviewing a learner from seven different schools around Cape Town. They had chosen the schools and they included schools in Khayelitsha (sites B and C) and Rondebosh and a few others.

The Video: *FACING The Truth: Talking to youth about AIDS*

The proposed video included interviews with learners in seven schools in the Cape Town area, including two private schools, four township schools and one inner-city school. Once all the details of the shooting schedule were worked out, they pared back to two private schools, one inner city school and two public township schools. In all they interviewed fifteen learners at five schools.

The Process

The proposal phase included submitting a written proposal and budget, working out the details with the group, deciding on a final format and a distribution concept. In this phase there was a great deal of discussion on 'why' they wanted to do this project, what aims it would fulfill, and how they would do it. The idea changed and transformed a number of times during this period. Mandla and I gave the group a list of questions that need answering in order to help them make their project a reality. They met on their own and answered our questions and their own internal dilemmas as well. By the end of this stage everyone knew what the project was all about.

Researching 'up'¹³

We had a session dedicated to discussing the possible implications of researching and filming in white schools where some members of the group felt less comfortable. Some of the group did not want to go to the white schools at all. Others felt it would be a good challenge, and the



Figure 7: Rustenburg Girls' School

main core of the group thought that it was integral to the project and they would go even if they were uncomfortable. Mandla and I led some discussion about the possible implications of what may happen in the schools in order to prepare the group on potential negative responses. We also talked about going into such wealthy schools where the learners may be very well educated on these issues and how this might feel. During this phase I was also discussing and bringing in some texts to the center we were working out of in Khayelitsha for further reading (such as Francis Fanon's *Black Skin, White Masks* (1965) and bell hooks' *Teaching to Transgress*(1994))

I was very excited about the fact that the group had decided to do some researching up. At the same time, given the political situation in South Africa, I was worried about throwing the group into a situation they were unprepared for. I tried to bring up my concerns with the group, but at first I was misunderstood.

¹³ By *researching up*, I am referring to researching above your social class.

One concern from the meeting was that Thozu mentioned that I had said the week before that the private school kids would be smarter than they were. I had actually said that they should be prepared for the kids also to be cool and knowledgeable, in a way I was trying to prepare them for what might go down and the racism or the opposite that might happen. I was concerned he misunderstood what I meant and resolved to be clearer in the future. It's difficult to figure out how to get across what I mean without offending the group while also preparing them for what might be a heavy situation. This is a lot harder than I first thought it would be, even with me as a gatekeeper to some of the white communities they might not have had access to otherwise.

Making Connections

The group arranged all the interviews with principals and selected schools. Their discussion on which schools to choose was quite extensive and they finally selected schools based on a number of chosen criteria. For the two private schools, I used my own connections there with arts teachers in order to get the project access. Teachers in those schools proposed the project to their classes and interested learners called either the project coordinator, Lindeka Rwida, or me. We also connected with some community video and arts projects and let them know what we were up to at this stage.

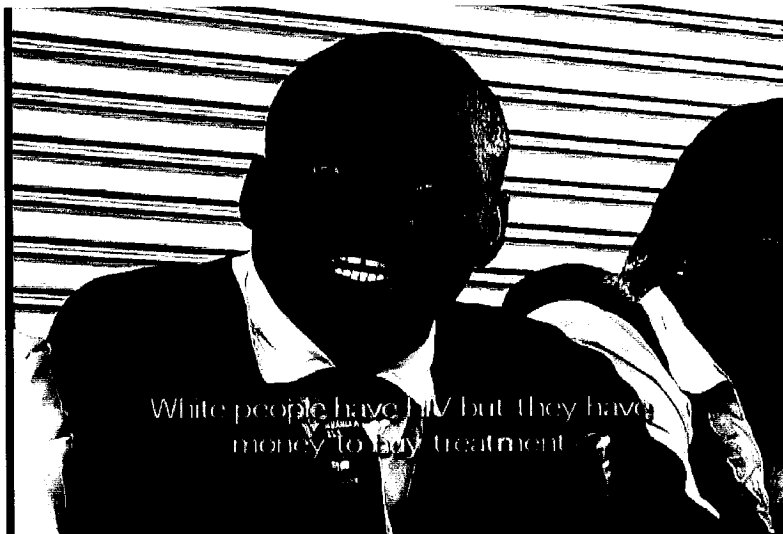


Figure 8: Spamandla High School, Khayelitsha

Pre-production

During the pre-production stage the group worked out the various roles for the film shoot and for the research phase. Each member had a specific role and a more general role as part of the team. They reached these decisions through consensus and Mandla and I played a very minor role in this phase, other than to alert them to roles or crew members they may have overlooked or might need in the field.

We also did a storyboard of the film and a shot list. This period lasted a number of sessions and we were also able to go through the equipment with everyone and teach basic video skills.

The film shoot

We had two days of production with multiple schools booked on each day. For a number of reasons (including space and time) they chose a small crew to send into the

schools. Mphumzi Xokozela was sound recordist and boom, Lindeka Rwida was the interviewer, Mandla Oliphant was the production assistant and KK Mofu was the camera operator and the default director. We had some technical problems with the equipment the first shooting day and had to return and interview different learners at the private schools again, which although frustrating at the time, turned out fine in the end.

Video Ethnography

By focusing on collaboration and the idea of ‘creating something together’, agency becomes shared between the researcher and informant. Rather than the researcher being the active party who both extracts data and gives something else back, in this model both researcher and informant invest in, and are rewarded by, the project. Recent work with video and photography shows how these media can be used to develop very successful collaborative projects. In some cases this has empowered informants/subjects and can serve to challenge existing power structures that impinge on the lives of informants and ethnographers.

(Pink 2001, 44)

A number of interesting insights emerged from this filmmaking process. Researching up of course presented a number of challenges for the group that I will discuss more detail. I was also very interested in the way the group constructed their images and topics in the various contexts.

There are three levels of intersection of the video making process.

1. The first is my observation on the process of making – how, why, and what happened with the FATT group. How the process happened and what we can learn from the process about what is important to young people in Khayelitsha in terms of AIDS. For me this is a critical element of this research – discovering what the main issues the FATT group identified as important for them to investigate and how that played itself out when they attempted to make their video documentary.

2. The second level of interpretation and analysis comes from the video material itself. In this case, I want to look at how the visual is an aspect of the research that FATT undertook that I, in turn, discuss now in an academic environment. What were the choices they made aesthetically and why? How did the video camera itself impact the research question they had chosen for themselves? In a sense, this is a very reflexive project. My research in this phase is focused on *their* research process. Some of these aspects inevitably overlap.

Pink discusses how Schwartz's (1992) "sociological interpretation was rooted in the research process – it regarded the images as subjectively and plurally defined, rather than having one single 'ethnographic' meaning or status" (101). As Pink argues, a reflexive approach to ethnography must allow for the images (and any other form of data) to be understood through the context in which they were created. For this project, then, the contexts and the texts that surround the making of the documentary are also elemental in uncovering and creating knowledge.

Thomas follows Geertz and Clifford in asserting that ethnography is 'not about making truth claims'. Instead, she sees 'the construction of ethnographic

descriptions’ as ‘an imaginative act which should bring us in touch with the lives of strangers’ (Thomas 1997, 143)

(Pink 2001, 12)

The act of making images, choosing frames, deciding on theoretical understandings, interviewing others – all of these aspects and more combined with the interpretation of that process through looking at the final images and montage is, of course, an “imaginative act” which contains various truths. As Ricki Goldman-Segall writes about her use of video ethnography in the classroom,

we are less interested in the one master story, the so-called truth, and more interested in multiple versions and the connections between them. We want to expand our points of viewing by including other’s points of viewing (Goldman-Segall, 4).

So, while looking at the process and data uncovered in the FATT video, I am interested in the multiple and intersecting versions of reality that the process laid bare.

3. The third and final aspect that is important to consider with the FATT work is how it fits within a concept of art as social activism and engaged pedagogy. In this level of reading I’m interested in how making and doing adds to a form of in-the-field pedagogy. Here I draw on Henry A. Giroux (1993, 1997, 1991, 1991a, 1998), Paulo Freire (1970, 1978), Michelle Fine (1994), bell hooks (1994, 1995), Jennifer Gore (2003), Peter McLaren (2003) and others who have explored theories of critical pedagogy, empowerment, feminist discourses and race theory. This work is an active project that seeks to uncover ways that pedagogy can be set in

motion in positive and proactive ways. As I will discuss below, the process of making the video itself became a type of “engaged pedagogy” where the learners being filmed and filming both were incited in a proactive way to deal with issues around AIDS, race, poverty, privilege, etc.

My analysis between these three elements intersects at times. For example, I might talk about how the group set up their shots and then comment on what was said during the interview. This is both observation on what I was researching (the process of a group of kids I’ve been working with, guiding their own research and investigation) and what they were researching (the new group of young people they interviewed and what those young people had to say about AIDS).

These various intersections can also become useful at this stage of analysis. For me, it is helpful to keep an eye on the reflexive nature of the process and understand that, while these ethnographies can tell us many things about this group of young people and their relationship to AIDS, this is only a partial truth. Rather than seeing this as problematic, I follow theorists such as Pink (2001) in examining the ways of looking at contradictions and varying readings possible in any given data, to uncover ethnographic richness.

Again, as I have found with *Fire & Hope* (2003), further interpretation happens when the video is watched and interpreted by an audience and provides yet another entry point into deriving meaning and ethnographic importance from it. As Morphy and Banks (1997) argue, “when [visual images] move from one context to another they are, in a sense, ‘transformed’; although their content remains unaltered, in the new context ‘the conditions in which they

are viewed are different' (16)" (cited in Pink 2001, 95). Showing the video footage to the whole FATT group in the middle of editing produced varied responses. Many in the group were surprised and amused by the two white boys' candor when they talk in the video about how they want to visit the townships and about how they are not sexually active. Showing a group of researchers, or a group of private school kids, or young people in Canada for that matter, would all shift the way the video was understood and viewed. For me, my interpretation intersects heavily with the knowledge I have about its production, the young people involved and the racially charged context in which it was produced. With all these elements in mind, I turn to the context of production more deeply to untangle some of what was learned in the process of making the FATT video.

Our first day shooting in the large boys' private school in Rondebosch was tense and awkward. Even though we were working through a very understanding and helpful professor in the school, I felt like I was suddenly leading the project more than I had been up till this point. The group froze in that school. As a researcher, I was a bit put off and uncomfortable myself. Here I was, in this big school with a professor I admired and who I had explained the 'student led' project to, and my group was hiding in the corner and I was doing a lot of the talking. I could feel myself flush.

I had expected that something like this might happen, and had discussed it at length with the group, but I was surprised at my own response to it. I was embarrassed that they were not leading and asserting themselves more, even though I knew that it was probably one of the more intimidating environments they'd been in. I was also concerned about how they were feeling, about if I was helping them feel comfortable, and about how we would move

forward. Finally—and thankfully—things became somewhat more relaxed as we located a few subjects who would be willing to talk on camera.

The first interview took place out in front of the school on the front steps. The wind was blowing hard that day and it made getting good sound difficult. The two boys being interviewed were framed with the stone steps and billowing trees blowing behind them. The cinematographer, KK, framed the boys beside one another, their private school blazers and pulled up uniform socks visible. The interviewees were surprisingly candid, and Lindeka the interviewer, stood near the camera (far from the subjects) loudly asking her questions. The boys told us that they were not afraid of getting AIDS. There was a perceptible distance between these boys and our film crew. At the same time they seemed casual and confident about what they were saying.

The next group of boys we interviewed were slightly older and they were sexually active. This time, KK wanted us to get out of the howling wind, so with the help of the boys, he found a quiet spot very secluded from the school grounds which led to the boys locker rooms. This time three boys were interviewed together. They were confident and cocky. They told us “black people have more AIDS because they are uneducated and don’t really know about the disease.” They claimed they used condoms always. They shifted foot to foot as the questions were asked and seemed happy when they could finally leave. The shooting this time was in a very tight proximity and there was an almost observable discomfort with how close we all were to each other. I wondered what would have happened if I had not been on the shoot with them. Would these boys have agreed to be interviewed by a crew of black kids from the townships?

Our last subject that day was filmed in an empty classroom. Lindeka point blank asked “Do you know your HIV status?” and the boy replied, “Yes, I’m HIV positive.” Everyone in the room, including the professor who was working at his computer, dropped dead silent. The boy smiled broadly at the camera and said again “I’m HIV positive...I mean, I mean...HIV negative.” He had confused the terms. It was a strange and intense moment. Perhaps mainly due to the broad smile and confidence with which he asserted “I’m HIV positive.”

I tell these anecdotes fairly superficially because the video footage from that first day was all lost. Due to a technical wiring problem to the microphone, all the sound was garbled and we couldn’t use it. At the end of the day the crew gathered at my house to look at what they had done and that was when we realized that our day’s work was gone. Everyone was very disappointed, especially since it was our first day and we had interviewed boys and girls at both private schools and they felt that they had really gotten some great and telling interviews. A lot of the racist underpinnings to the way AIDS is perceived in their communities was present in those interviews. It was hard to imagine what to do next. The group was disappointed and dejected. It was their first attempt to confront a white community they were intimidated by in this way, so it seemed like a failure on many levels.

KK tried not to show his disappointment to the group, but it was written all over his face. Though we were all tired from a long day of shooting, we decided to make a plan to go back to those schools. The group talked about why those schools were important and what they really needed to get there. For them, hearing the voices of white kids talk about AIDS

was really critical. White voices are so often silent from the AIDS discussion in South Africa and it was a serious and critical lack in their minds. They felt that black kids needed to see these white kids talking about AIDS. It was also really critical to the group that the racist underpinnings to AIDS were made clearer. Access to doctors, treatment and healthy food were things that didn't get talked about publicly a lot, but were fundamental to the way the virus flourished. In these interviews they had decided to ask about access to these things and the white kids had seemed to be getting the message that their wealth was protecting them. Again, I found there was a level of education in action that was happening as part of the process of interviewing and taping. The questions themselves had things to tell the interview subjects. Finally everyone resolved that I would arrange times with the schools and we would go back. At the boys' school, though, the group decided to interview new people so as not to embarrass themselves or reveal their error to the boys they had met thus far.

A few days later we returned to Rondebosch Boys' School and interviewed two new, younger boys. These two were a bit more open. They were younger and were more genuinely concerned with what was happening in the townships. To all of our amazement they also seemed very self-aware and commented during the filming about how they really didn't know the answers to some of the questions and were surprised how ignorant they were. This interview was also shot in the small enclave outside the boys' locker room, out of sight from the rest of the school.

After this interview was over and I was driving away with the crew there was a lot of animated discussion about what the boys had said. The crew was particularly interested in a

few things the boys had said. Andrew said, “I don’t think you would have difficulty getting access to medication in my community... [long and thoughtful pause] but there might be long queues.” They also were very candid about their sexual practices (or lack thereof) and told the camera crew that, “we practice safe sex because we don’t practice sex... We reserve the right to say NO!” while also making it clear that they would jump at the chance to start “practicing sex.”



Figure 9: Rondebosch Boys' School

The shooting that happened in the townships took a very different tone and quality. The interviews there went quite differently than the private school interviews. These interviews had been set up entirely by the FATT group who had made trips or phone calls to the principals ahead of time to alert them about our project. This time, everything was in Xhosa and it was only me who was the odd one out. During the brainstorming phase it became very important to FATT to conduct interviews in mother tongue languages. This might have been a problem, they admitted, had they gone to Afrikaans schools since none of them spoke Afrikaans, but after all, they choose English and Xhosa schools exclusively.

KK walked confidently into the first Khayelitsha school like he owned the place. Gear in hand, the small crew smiled and waltzed around the schoolyard looking for teachers and the principal. This Khayelitsha public school was a totally different environment from the private schools we had filmed the day before. It was noisy and dusty. Kids were running around outside, laughing and sitting chatting in groups. The stone and cement hallways of the Rondebosch school seemed eons away. KK was obviously in his element. I was shocked at the difference in the crew, though I could have anticipated it. Their body language and attitude made it clear that that they were on 'home ground'. KK even went so far as to open a classroom door (with class in session) and ask the teacher if they could have a word with the pupils about being in the video.

More surprising to me was the way that the group chose to frame these interviews. Whereas in Rondebosch the interviews were in quiet and secluded places, KK was bound on shooting the interviews in the classroom with the entire class present. This was a bit of a feat to accomplish, since there were close to fifty students in the room and they would all need to sit quietly while the questions were being asked. For him, it was the only solution and the rest of the crew agreed. The rest of the school grounds were quite noisy anyway so if this is what they wanted, they needed to make it happen. I was almost an invisible member of the group at this point. I say 'almost' because I am a white foreigner and a white person is never invisible in Khayelitsha and certainly the teachers, principal and students were making their own assumptions about what a white woman was doing with this group. Although they introduced the project as a video they were making and told a little about their group, it was clear that my presence altered people's attitudes about what FATT was

doing. Ultimately (and the kids told me later) it was probably a bit of a help to convince people to participate in the project. Still, I tried to hide myself as best I could, keeping totally silent and just helping KK if he needed me. It was interesting that at first when asked if they wanted to be interviewed, the students asked if they would have to speak in English. When they were told that they would be interviewed in Xhosa, everyone was far more enthusiastic to be part of the project. Again I was reminded how important language is in South Africa. At first, some of the students glanced in my direction when they spoke Xhosa, as if unsure that it was really all right to offend a white person by not speaking English. In the end, I would nod my head now and then to make the students feel comfortable that they were not being rude. I was struck and saddened by the embedded deference to white people that are still so prevalent.

Quickly, I understood that the act of filming in the school in Khayelitsha had far different implications and motivations for the group than the other interviews had. For one, having a camera and equipment as we did was very impressive and lent the group a special status in the eyes of everyone at the school. The FATT crew seemed like really important people and this put them in a slightly higher esteem than the young people they were interviewing. So while they were in a familiar environment, they were not 'one of the class' but instead, had a bit of a special status during the course of filming. At first, I speculated that this was what might have led KK to want to frame shots of the subjects in the large classroom. It was obviously much more difficult, so there must have been some motivation. Status seemed definitely to be one of the motives.

As the interviews went on, I realized that another motive that had warranted the whole class participation in the interview appeared to be education. KK and the other crew members seemed to want as many people present as possible to hear and talk about the issues. These youth are activists in Khayelitsha and they are very dedicated to spreading the message about HIV prevention and AIDS education. Their understandings of the issues as social problems rooted in inequality seemed to be something they wanted to openly talk about in the classroom. While they were not giving a lecture, the questions they asked led the other learners in the class (if they were listening) to think about race, poverty, access to medication etc. Video, in this context, became part of an engaged pedagogy that used its high esteem and social status as an entry point to gain attention from learners and focus that attention on AIDS. For me, this was a very unexpected result of the use of video in the classroom.

For whom do we shoot this footage when we collaborate with individuals and groups who also have an interest in the footage? Such collaboration results in ethnographers working with informants and participating in 'their' video culture, as well referring to other video cultures. (Pink, 85)

We began to explore some of these 'video cultures' during the filming.

At Spamandla High School we were also struck by some misinformation given by a student. This young girl told Lindeka that she did not want to use a condom until she was tested for HIV – and she was sexually active. The group was taken aback and Lindeka asks her the same question again twice to make sure what she was hearing was correct. After the

filming Lindeka talked more to the girl about what she had said and tried to give her some basic education on HIV. The scary part for everyone in the crew was that the health educator at that school recommended this girl. The crew was frustrated and confused by the girl's lack of knowledge, although KK was happy that we recorded a moment of real 'ignorance' on tape. He felt that there was a lot of ignorance to be overcome around the issues and it was an important element to address. The crew was further frustrated by the fact that the white kids they had interviewed had been far more articulate than the black kids had been. Should they use this interview in the final tape? Does the interview reinforce negative stereotypes about black people that they were trying to avoid? Of course the video project, which only interviewed a small number of youth, was in no way indicative of a general attitude in any community, but, was that what they hoped it would do? Many of the questions I had remained unresolved and the piece with the girl's poorly informed comments ended up in the final video.

Ultimately, I am just touching on the surface of some of the issues that were uncovered during the filmmaking process. The video itself tells its own stories about the interviews with the various youth in the schools. For the purposes of this research, I found that the most important elements I took back to my own project were the emphasis the group placed on issues of race; access to medication, food, housing, medical treatment; poverty; and the emphasis on pregnancy rather than HIV prevention. They were genuinely interested in hearing what the reality of AIDS was like for white people. These were the critical areas that FATT were concerned with and were anxious to explore. The group was very keen to hear the stories of other young people in South Africa and wanted to go to as many schools and

talk to as many learners as possible. Again I was reminded about the importance of stories and how much we need to provide spaces in which people can hear each other's stories.

Post-production

Based on the storyboards and discussion in the group sessions, as well as the post-interview discussion from the crew, I edited the material into a 15-minute video. The group watched the rough cut and made some suggestions before finalizing it. The final video and the master tape was given to the group and they are currently making plans for screenings and further work with the piece.

On one of our last days together we ran a group evaluation. At the end of the evaluation, all of us gathered out on the lawn and with the help of my laptop, watched the final video play itself out. Of course not everything the group wanted to happen in the video turned out the way they wanted, but it was amazing to see everyone peering in and watching with rapt fascination. We had lost some of the more blatantly racist interviews when we had technical problems, and the white kids in the final video came off very well overall. There was a constant flux between whether the FATT group wanted to demonize the white kids or whether they really just wanted to know what was going on 'out there'. In the end I felt like they weren't sure themselves. They knew that there were things they didn't know. Some of the most significant benefit for the group was the knowledge that they could walk into a space like a private school and be acknowledged and respected. Their worlds were so far apart, but they shared many things in common as well.

A month after the project was finished they began earnestly trying to form the FATT group into an organization with the support of a local organizational development NGO named Connections who have offered their services to the group. They have a number of plans for the video and for future projects. Funding, of course, is always an issue but they have some creative solutions on how to solve immediate funding dilemmas at this stage. I also left them with notes on what they did, connections we made during this project and some thoughts for the future.

Summary

The video workshops, while by no means an extensive process did provide some insight into how video ethnography could be used as a tool for collaboration with young people around social issues. In this case video and film were used as an ethnographic research tool, an aspect of creative social intervention and as a vehicle to explore more thoroughly the accounts and narratives of young people. While these accounts can be problematic in the context of how we represent ourselves in video interview settings, this very presentation can be the source of interesting data collection. Involving young people as 'knowers' and creative agents in this process also can create a situation where an engaged pedagogy is possible.

As I found with the Khayelitsha group, the public act of filming and the status it allowed them, also created a space to investigate a type of peer education in-the-field. Video research also allows us to play back in different contexts the material from the field and allows for new levels and layers of data to be collected around the response from other viewers in other situations. Finally, the videos themselves are objects that stay in the field

for the participants to continue using in their own ways and with their own motives. This aspect in itself can lead towards a version of *Arts-informed social change/research* I discussed in Chapter One.

CONCLUSION

In this thesis I have touched upon various aspects of the research I conducted with South African young people around HIV prevention. Primarily, I have been concerned with engaging South African young people in exploring ideas around *arts-informed social change* as a method for engaged, activist research and transformation. I was investigating how action based participatory methodology could involve youth as actors both in telling their own experiences of HIV/AIDS in their lives, and by contributing to the overall strategies in HIV prevention education and AIDS awareness in their communities.

Throughout the preceding chapters, I have tried to show how a multidimensional look into the lives of young people is necessary to unpack some of the social issues they are faced with around HIV/AIDS. I have argued here that the use of arts such as video, writing and drawing can provide an entry point for engaging young people on a deeper level with these issues. Throughout I have also linked research with education, or “engaged pedagogy.” It is imperative that during the AIDS pandemic we find ways to conduct action-based research that gives something concrete and connected back to the communities under study that may enable further building of social capital, critical consciousness and a more complex understanding of power relations. In doing so, action-based research could aid in the construction of “health-enabling communities” (Campbell 2001).

Further to that, I have also found in my research in South Africa that violence and gangsterism poses a serious threat to the building of such a “health-enabling community”

and I have tried to argue for a more thorough investigation into the violent climate South African youth live in, as well as HIV prevention strategies that specifically take into account violence as well as gender issues. I have also paid specific attention to the gendered dynamics of the AIDS pandemic and have argued for more “thick and deep” research that attempts to understand the contradictions, omissions and variances that occur in young women and men’s accounts of their lives. In doing so, we may also be able to understand the spaces between *theories-in-use* and *espoused theories* that may allow young people to convince themselves they will practice safer sex, yet be unequipped or unwilling to do so.

Reflecting back through the thesis and fieldwork there have been so many issues and ideas that I have not had the space to discuss in more depth here. At the same time, there are a few points I would like to reiterate.

1. The first is the critical importance of giving young people an active way to participate in discovering and researching key issues around sexuality and HIV/AIDS in their communities and in their lives. Throughout the project I found that the more actively engaged the participants were, the more they gave back to the process through their own interventions, peer education and active community involvement.

2. Secondly, actively involving youth and working with a participatory, arts-based methodology also can allow for the tensions and contradictions between *theories-in-use* and *espoused theories* to be exposed and explored. Aspects such as social identity, critical consciousness, social capital and power were critical in how the young people constructed their identities and were able to participate in a “health-enabling” environment.

3. Thirdly, violence is a critical issue in the lives of young people and needs to be more substantially addressed in HIV prevention projects. Community violence reduction projects could do a lot to create an environment of social capital where HIV prevention would actually be much more possible.

There were many issues that might have come up with youth in other contexts but didn't in this particular research. For example, a significant area where my research made few findings but that I'd like to comment upon here is in respect to Men having Sex with Men (MSM). This area of research has significant differences in South Africa than in North America and I felt ill equipped to deal with the very distinctive ways that MSM and homosexuality was associated with AIDS and dealt with in the country. This was also somewhat of a recruiting issue, since we focused our recruiting on including the different racial groups in South Africa as much as possible, but did not ask specifics about sexual practices in any of the group discussions or recruiting phases. Since many of the youth were underage, it felt more ethical and appropriate to allow them to speak generally about sexuality without asking specifics of sexual practices. It is interesting that Cape Town is very open sexually with a huge Pride celebration every year that attracts people from all walks of society. While I do not feel that I have made a pointed study of issues that MSM have to deal with in South Africa, there are a few points that I picked up on over the few years I have spent there.

I was continually happily surprised at the lack of homophobic attitudes the young people displayed. In the symposium we held during the Soft Cover project, Sello Duiker, a South

African novelist, read from his most recent book *The Quiet Violence of Dreams*. The book, which is set in Cape Town, follows a young man as he finds his identity through working as a sex worker in Cape Town's gay village. When we asked Duiker to do a public reading from the book, the young people in our group gathered at his feet as he read a very explicit passage of homosexual sex. Later in the discussion groups there was lots of talking about the 'sexiness' of the passage, but not one of the young people commented on its homosexual content and they all seemed to think he was just fantastic.

I was also interested to find that the boys from Khayelitsha who have worked with TAC's leader Zackie Achmat (who is an openly gay HIV positive man who has fought for gay rights as well as the rights for people living with HIV and AIDS) never made any mention or comment on Zackie's homosexuality. Honestly, some of these incidents confronted my assumptions that there would be strong homophobia in communities like Khayelitsha, and although it is hard to make much of incidents like these, it has prompted me to think that the South African male relationship to sexuality and masculine norms is complex and deserves investigating in and of itself.

While I did not find significant levels of homophobia in my group, there was some discussion about homophobic attitudes in Atlantis in one of the interviews for the *Fire & Hope* video. In this case Morgan, when questioned about gender stereotypes, commented that his more "effeminate" behaviour had prompted teasing by other kids at school. His sister was also a very tough tomboy who would threaten people physically. He said that because she was so tough he was never afraid to walk around by himself, but that there was a lot of confusion and rumors going around about his sister until she was married. From his

comments it was clear that there were homophobic attitudes in Atlantis but it also seemed that he had found a way to deal with the attitudes.

Finally, I have not touched much on the very real issues of stigma and discrimination that people living with HIV and AIDS in South Africa have to deal with. Again, I do not have the space to address this issue here, but it is a critical topic and one that must remain in our awareness of how projects with young people are structured and run.

There is so much investigation and education to be done in this area. While this research only scratches the surface of some of the issues that young people face, continuing to provide spaces for young people to actively participate in educational and activist projects is an essential contribution to the fight against AIDS.

I would like to end with a poem by Lesley-Anne from Atlantis that reminds us how important young people are to this struggle and to reminding us of our responsibilities in a just society:

I live life striving to achieve my goal
To become an archeologist
I wish people could see AIDS the way I see it
My uncle lived with AIDS
every day I was there to help him with everything
cause my family was too scared
I hated seeing him suffering and that broke me when he said his last
words

He called me

Thanking me for everything I did.

At his funeral I was so sad

and thinking about the good times we've had

I always think of the good times instead of the bad times

Living life to a goal

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APPENDIX A: *Fire & Hope* and the *FACING The Truth* Video

APPENDIX B: *Atlantis: Young people write and illustrate the impact of HIV/AIDS on their lives*

APPENDIX C:

Handout *Getting the Facts about HIV/AIDS*

Handout *Social Aspects of HIV/AIDS: Gender*

GETTING the FACTS about HIV & AIDS!

HIV (Human Immunodeficiency Virus)

Your immune system keeps your body strong and free of infections. It is like a guard against^a disease. When you get infected with HIV, your immune system can be weakened, making you more vulnerable to infections and diseases. HIV infects and kills the cells that help your immune system detect infection and disease and fight against it. These cells are called CD4, or t-cells. HIV lives in the bodily fluids (like blood, pre-ejaculate fluid, breast milk, vaginal secretions and semen) and is transmitted if you come in contact with fluids from a person with HIV.

The main ways that HIV is transferred is through **sexual contact** without a condom. To protect against this happening, you must use a male or female condom every time you have sex, or abstain from sex. There is also a risk of transmitting HIV through unprotected oral sex, although the risk is lower. Oral sex can be risky for the person using his/her mouth when there are open sores in the mouth or bleeding gums, or when semen enters the mouth and when any secretions are swallowed.

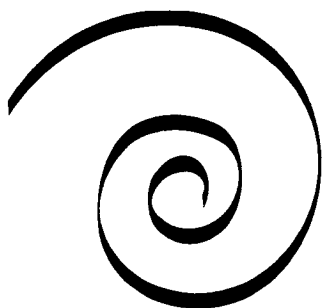
Other ways that HIV is transmitted:

- Blood and Blood Contact
- Mother-to-child transmission (MTCT)

Blood Contact can occur through sharing needles and equipment used for injection drugs, through organ transplants or blood transfusions, and through sharing tattoo or skin piercing equipment. To avoid these transmission routes, you should never share needles or any equipment that comes in contact with blood.

HIV can also be passed from mother to child during **pregnancy, birth and breastfeeding**. If you are pregnant and HIV positive or want to get tested, you should speak with a health care provider or AIDS clinic to find out what you can do before the baby is born to reduce infection. They can also advise you on how to prepare formula for your baby instead of using breast-milk, which is another route in which HIV is transmitted.

Even if you have HIV, you can keep your immune system strong by staying healthy, exercising and eating well. Having HIV doesn't mean your life is over. You can still enjoy a happy, healthy life if you take good care of yourself and keep your immune system strong.



see next page for info on AIDS...

GETTING the FACTS about HIV & AIDS!

AIDS (Acquired Immune Deficiency Syndrome)

A normal CD4 count is 1,150. When your CD4 cell count is less than 200, you are considered to have AIDS.

AIDS is a collection of infections that occur once HIV has deteriorated your body's ability to combat diseases. If you have HIV, you will not necessarily develop AIDS. There are a whole bunch of different illnesses that are associated with having AIDS.

Neither HIV or AIDS has a cure, but there are drug treatments called anti-retrovirals (ARVs) that can delay the onset of AIDS. A healthy immune system will also delay the onset of AIDS.

Ways to avoid HIV infection:

Sexual Contact

There are several ways to avoid infection through sexual contact -
Abstain from sex, or if you do have sex, use a male or female condom every time. You can also reduce your risk by avoiding having multiple sexual partners and avoiding putting yourself in risky situations where there is a chance that coercive sex or rape may occur (such as places where there is a lot of drug and alcohol use)

Blood and blood products

Do not share needles or injection drug equipment with others, make sure that any equipment, including tattoo, piercing and circumcision equipment, is properly sterilized.

Mother-to-Child Transmission

Women can be tested for HIV during the antenatal period and if she is HIV positive (or if her partner is HIV positive) there are some different things that can be done. She can be counseled on her options and may receive treatment that could reduce the risk of transmission to the child. There are also things that can be done during the baby's delivery to minimize the risk of infection, such as having a Caesarean section, or receiving Nevirapine. After the baby is born, using formula instead of breastfeeding can also reduce the risk of infection. It is important, if you are pregnant, to talk to your doctor about your options.

Delaying when you start having sex is one of the best forms of protection for young people.

You can also avoid HIV infection by practicing other forms of safer sex like kissing, masturbation, using hands to stimulate your partner, dry humping, oral sex on a man or woman using a condom or a latex sheild.

Social aspects of HIV/AIDS: Gender

Why is gender an HIV/AIDS issue? Gender refers to the social constructions that define the roles of women and men are expected to fulfill in a culture. Gender norms define the way girls and guys are 'supposed' to behave. For example, in some cultures women may be expected to be homemakers and men are expected to be tough and non-emotional. While gender roles and norms change from culture to culture, in most parts of the world, men tend to have greater social, political and cultural power and privilege. Gender roles have an impact on HIV vulnerability for a number of reasons for both young women and young men. Young women are specifically more vulnerable to HIV due to gender imbalances.

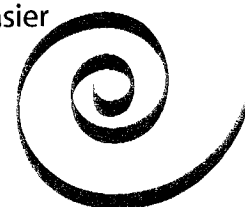
Young Women's vulnerability and risk

Young women represent the fastest growing group of HIV infections worldwide. This is because both social and biological factors make young women vulnerable.

1. Biological vulnerability

Young women are physically more vulnerable to HIV infection than young men because:

- Girl's vaginas are more likely to tear through intercourse facilitating HIV infection
- STIs are harder to recognize in women than men, and having an STI makes it easier to contracting HIV
- There is more surface area on the female genital tract than on men's
- There is a higher concentration of HIV in semen than in vaginal secretions
- There is more semen exchanged during sex than vaginal fluid



2. Social and Cultural Factors

The main cause of young women's vulnerability to HIV comes from unequal gender relations and social norms.

While young men are often encouraged to have multiple sexual partners, young women are often expected to be 'innocent' when it comes to sex. This makes it harder for women to talk about safe sexual practices with their partners, who might classify them as 'sluts' for bringing up the conversation. Because in society men often have more power in social relations, young women are also vulnerable to being coerced into having sex before they are ready.

Young women are especially vulnerable to rape, which can facilitate HIV transmission. Young women are often raped through the use of violence and force, which makes it more likely that there will be tearing of the genitals and possible HIV infection.

Men are also more often the ones making decisions about when and where sex takes place and if a condom is used. This can make it difficult for a girl to negotiate condom use with her partner. Young women are also more likely to have older male sexual partners who are more likely to have already been exposed to the HI virus. Age differences also makes girls less powerful in the relationship and have more difficulty insisting on condom use.

Access to education

All around the world policies and laws exist which prevent young women from using contraceptives till they reach adulthood, or prevent girls from gaining access to information about safe sexual practices and clinics that teach about reproductive health. Many cultures think young women should not have sex before marriage, which might prevent them from receiving life saving information.

Economics

Women have less access to economic power than men. Girls who have been orphaned or have family members who are sick are often heading the household. They may drop out of school and miss out on valuable information about safe sexual practices, or they may also feel that they need to turn to survival sex to get by. Sex exchanged with older men for taxi fare or for basic necessities and girls puts girls in a position where it is very difficult to insist on condom use.



Young Men's vulnerability and risk

Young men are often expected to be knowledgeable about sex and so they don't feel comfortable asking questions about how to protect themselves. Gender roles also expect men to have many sexual partners that put them at greater risk of HIV infection. Young men are also expected to use drugs and alcohol and lead a more 'carefree' risky lifestyle.

Young men who have sex with other men may also be afraid of discrimination and stigma from being open about their sexual practices. This can make it difficult to reach these young men with prevention messages, and may also limit their access to clinics and information networks.